AN EVALUATION OF A FAMILY DECISION GUIDE

by

Janelle Renée Zerr

BScN, The University of Saskatchewan, 2004

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ABSTRACT

Family caregivers (FCGs) are essential to a patient’s ability to be cared for and to die at home. In order to provide care at home, FCGs require support, but such support is lacking. The Family Caregiver Decision Guide (FCGDG) is an intervention that was developed based on the findings of several studies, and aimed to assist FCGs to navigate their way through the decisions and processes of caring for their palliative family members at home. The purpose of this pilot study was to field test the FCGDG with bereaved and current FCGs for someone who has advanced cancer and is considered to be in the palliative phase.

Qualitative data was gathered in two separate phases. In the first phase, the research team conducted three focus groups with bereaved family caregivers (total n=14). In the second phase, I conducted cognitive interviews with current family caregivers (n=8). All interviews were audio-recorded. A qualitative descriptive approach was used to conduct an inductively driven content analysis of the data for both phases of the research. Data from phase one of the research was used to amend the FCGDG prior to phase two of the study.

We learned that various factors either helped or hindered participants’ connection and subsequent engagement with the guide, particularly the images and the format/layout of the guide; the guide was re-designed twice in relation to participant feedback. Some participants requested that the guide be more explicit about end-of-life issues; however, findings revealed complexities surrounding this issue. It was further noted that when the focus of the guide was on the FCG, specifically their self-care instead of the ill family member, it disrupted their connection to the guide and compromised the effectiveness of the intervention. Based on feedback on the FCGDG, the guide shows promise as an effective intervention. However, it
was determined that the guide should not be used as a stand-alone tool; it was recommended that the FCGDG be used in conjunction with navigational support.
PREFACE

I was involved in all aspects of this research study. I played a role in all the focus group interviews, either taking field notes or conducting the interview, and I conducted all the cognitive interviews. I was responsible for the analyses of the research data and the preparation of all drafts of the thesis. My supervisory committee assisted me with the identification and design of the research program and provided many helpful comments in the revision of my thesis.

This research was approved by the University of British Columbia Behavioural Research Ethics Board (Phase One Ethics Certificate# H12-01645, Phase Two Ethics Certificate # H14-00285).

This research received harmonized ethics approval from the University of British Columbia Behavioural Research Ethics Board and the Interior Health Research Ethics Board (Certificate # H14-00285-A003) for Phase Two.
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DEDICATION

To my mother, Deborah,

For modeling to me that I could succeed.

&

To my mother-in-law, Carol,

For support that allowed me to succeed.
Chapter 1. INTRODUCTION

1.1 Background

A patient’s ability to be cared for and to die at home largely depends on family caregivers (FCGs; Stajduhar, 2013). Consequently, families have been recognized as an intrinsic part of patient care, because they provide the majority of physical and emotional care for individuals with advanced life-limiting illnesses (Bastawrous, 2012; Funk et al., 2010; Stajduhar, 2013). As informal caregivers of these individuals, FCGs have countless responsibilities, both within the home and in the healthcare system (Bastawrous, 2012; Funk et al., 2010; Kruthaup, 2007; Robinson, Pesut, & Bottorff, 2012). However, in order for FCGs to provide care at home for as long as possible, FCGs require support and guidance to navigate their way through the decisions and processes of caring for their palliative family member, as well as an understanding of the intricacies around care required at end-of-life.

End-of-life care continues to be critically important to Canadians as the number of seniors aged 65 and older is projected to increase by 25% between 2005 and 2036, and the number of deaths by 65% (Fowler & Hammer, 2013). Already, according to Statistics Canada (2012), 2.7 million Canadians aged 45 and over provide 80% of care needs for their family members with chronic and advanced life-limiting illnesses. Moreover, 87% of Canadians aged 55 and over wish to live at home for as long as possible (Canadian Institute for Health Information, 2011) and wish to die at home or in a non-institutionalized setting (Edwards et al., 2012; Fowler & Hammer, 2013; Stajduhar & Davies, 2005; Topf, Robinson, & Bottorff, 2013). However, that is not where the majority of expected deaths occur (Fowler & Hammer, 2013; Topf et al., 2013). There are a number of reasons why this might be so.
Individuals continue to care for their ill family members at home for as long as possible in an attempt to honor their family member’s wish to die at home (Topf et al., 2013); however, evidence suggests that they are often challenged in their ability to provide the excellent care they strive for. For one, they experience multiple competing demands such as the care for older family members, younger family members, and work outside the home (Robinson et al., 2012; Stajduhar, 2013). In addition, FCGs face further challenges in their caregiving role, as patients are living longer and consequently have more complex needs (Hudson & Payne, 2011; McMillan, 2005; Meeker, Waldrop, Schneider & Case, 2014). Accounts of FCGs’ experiences make it increasingly apparent that the decision to care at home has a profound impact on families because of the demands and difficulties that can be associated with caregiving (Robinson et al., 2012; Stajduhar & Davies, 2005; Topf, 2012; Topf et al., 2013).

FCGs have a tremendous need for increased support when caring for someone with advanced life-limiting illness. Topf (2012) described this need in her thesis work, which explored the experiences of families caring for a family member with an advanced cancer, when a home death was desired, but not achieved. Her research revealed that those desiring a home death faced a number of challenges: a lack of preparedness for caregiving, difficulty with accessing professional support and information, and inadequate help. Topf’s study indicated that FCGs were often unprepared for the in-the-moment decisions they made throughout caregiving, did not know what they were getting into, experienced a lack of support, required critical knowledge and skills, and often learned by making mistakes. Furthermore, findings showed that FCGs were deeply committed to providing excellent palliative care, and often risked their own health to support their family members’ wishes and
preferences. The need for a decision guide to support family palliative caregivers arose from such findings (Robinson et al., 2012; Topf, 2012).

Additional supports for FCGs are in the interests of everybody. Because of the aging population, the need to keep patients with life-limiting illnesses at home and avoid institutionalization for as long as possible is considered essential to the sustainability of the health care system (Stats Canada, 2007). The Canadian health care system has been under strain due to the aging demographic resulting in increases in life-limiting illness accompanied by rising health care costs as well as staff shortages, which have resulted in more care being shifted into patients’ homes (Carstairs & MacDonald, 2011). In this way, FCGs have assumed more responsibilities, once provided by nurses, in the context of government cost constraints (Funk et al., 2010; Stajduhar & Davies, 2005). In light of political and economic changes, the need for individuals to care for their dying family members at home is now well recognized (Bastawrous, 2012; Crooks, Williams, Stajduhar, Cohen, Allan, & Brazil, 2011; Stajduhar, 2013). In fact, in order for palliative care to be effectively supported in the home, both FCGs and home health care services are required; however, in Canada, the latter has been difficult to access (Stajduhar et al., 2010), and in many countries support for FCGs has been suboptimal (Hudson & Payne, 2011). Consequently, the quality of life for individuals who require palliative care could be tremendously compromised without the support of FCGs, who continue to facilitate patients' most common request to live at home for as long as possible, and for some, to die at home (Hudson & Payne, 2011; Stajduhar, 2013).

As various factors have increasingly shifted care into homes, a heightened urgency remains to meet the needs of FCGs as critical healthcare partners. A wealth of literature has described FCGs’ experiences; however, FCGs require tangible support and knowledge to
continue to provide care at home (Bee, Barnes & Luker, 2008; Stajduhar, 2013). This need for support was the impetus behind the development of a decision support guide for family palliative caregivers. Decision support aids are tools used to support individuals in making complex health-related decisions (O’Connor, Jacobsen, & Stacey, 2002; Stacey et al., 2014). FCGs of individuals with an advanced cancer could greatly benefit from the support offered from such a tool.

1.2 Purpose of Study

The need for a decision support guide to assist FCGs became apparent from the findings of several studies that explored the experiences of FCGs (Funk, Allan, Stajduhar, 2009; Hudson, Aranda, Kristjanson, 2004; Robinson et al., 2012; Topf, 2012; Topf et al., 2013). Based on FCGs’ need for decisional support, Dr. Carole Robinson and colleagues developed the Family Caregiver Decision Guide (FCGDG). The FCGDG was designed as a step-by-step process, which addresses more common FCG issues at the start of the guide and progresses to more sensitive topics near the end. The guide provides FCGs the opportunity to review various aspects of caregiving while answering questions concerning their individual caregiving situation and needs. The content is presented with many short phrases and tick boxes to increase the guide’s ease of use. ¹

The aim of the FCGDG is to assist FCGs to navigate their way through the decisions and processes of caring for their palliative family members at home and furthermore to assist FCGs in understanding the intricacies around the care they would be giving. The guide is a structured interactive tool that engages caregivers in assessing their needs, values and

¹ For more information on the FCGDG, contact Dr. Carole Robinson @ carole.robinson@ubc.ca
preferences for care, available supports and resources and determining best options for care. Though the development of the FCGDG was informed by empirical findings, the decision guide had not yet been field tested with users, as recommended by the International Patient Decision Aid Standards (IPDAS) Collaboration in their developmental process standards (Elwyn & O’Connor, 2009). Hence, the purpose of this pilot study was to field test the FCGDG with bereaved and current FCGs for someone who had advanced cancer and was considered to be in the palliative phase. More specifically the following questions guided this pilot study: (1) Was the FCGDG acceptable to FCGs? (2) Was it readable and understandable for FCGs? (3) Were the choices and decisions presented in a neutral way? (4) Was the FCGDG applicable to their caregiving situation? (5) Did the FCGDG assist in identifying the decisions that must be made and in making choices around those decisions? These questions helped to address the ultimate goal of this study, which was to improve the quality and utility of the guide in helping FCGs make decisions related to the provision of palliative care, prior to using the FCGDG in future studies.

1.3 Definition of Terms

**Family.** For the purposes of this study, the “family are who they say they are” (Wright & Leahey, 2009, p.50).

**Family caregiver.** For the purposes of this study, a family caregiver was defined as an individual with key responsibility for the health care, psychosocial support, and daily needs of an individual with advanced cancer as this thesis builds on the findings of Topf’s (2012) work with this population. Furthermore, with cancer patients it was relatively ‘easy’ to identify when cancer was advanced and palliative care was needed. Given the broad definition of family, a caregiver could be someone who was traditionally considered a family
member or someone who was a close friend or neighbour.

**Advanced life-limiting illness.** For the purpose of this study, an advanced life-limiting illness was an advanced cancer, which limited the individual’s length of life. (The individual with advanced cancer, meaning the cancer has metastasized and cannot be cured, was considered to be in the palliative phase.)

**Family Caregiver Decision Guide (FCGDG).** This decision support guide was an aid consisting of options, criteria and information to offer educational as well as values-based decisional support to FCGs.

**Palliative Care.** For the purposes of this study, palliative care was defined as that which was aimed at relieving suffering, providing dignity, and enhancing the quality of life for individuals dying from advanced illness, their caregivers, or those who were bereaved (Canadian Hospice Palliative Care Association, 2013).
Chapter 2. LITERATURE REVIEW

2.1 Overview

In recent years, there has been a growing emphasis on the provision of home-based palliative care, both in Canada and internationally (Chai, Guerriere, Sagorski & Coyte, 2014; Payne & Grande, 2013). It is well documented that FCGs carry much of the responsibility associated with caregiving in the home, specifically at end-of-life (Chai et al., 2014; Hudson & Payne, 2011; Robinson et al., 2012; Stajduhar, 2013). However, FCGs are often ill-equipped for the enormity of the challenges associated with palliative caregiving and caregiving at end-of-life (Robinson et al., 2012; Statistics Canada, 2012; Topf et al., 2013). Despite the demands associated with caregiving, FCGs remain committed to providing excellent care to their family members who have advanced illness, but often lack the support needed to accomplish this goal (Robinson et al., 2012; Topf et al., 2013). This chapter addresses both the context of family caregiving and the experiences of palliative caregivers to better understand the critical importance of the family caregiving role as well as their need for support.

The first section, the context of family caregiving, covers a broad background that begins with Canada’s aging population, its impact on the increase in chronic and life-limiting illnesses (specifically cancer) and the implications they have on the health care system. Also discussed, are patients’ desire to die at home and the necessity of FCGs to make this possible.

The second section describes the experiences of palliative caregivers and includes a discussion of FCGs’ desire to provide care despite their frequent unpreparedness and lack of support. Furthermore, the intensity of FCGs’ role often carries consequences to their own wellbeing. This review of selected literature lays the groundwork for the argument that given
the need for FCGs and their desire to care for their family members at home amidst challenges, additional support is required to ensure that FCGs can keep on caring as long as possible.

**2.2 Context of Family Caregiving**

A broad view of the literature allows for a better understanding of the context of family caregiving within the current health care system and appreciation for the many factors that contribute to the need for FCGs.

**2.2.1 An aging population**

The aging Canadian population is of relevance to this discussion because older Canadians are more likely than younger Canadians to face the diagnosis of a life-limiting illness (Teixeira et al., 2012). In Canada, the number of seniors aged 65 or older was estimated at 5,186,800 in July of 2012 (Statistics Canada, 2012) and in British Columbia alone, the percentage of seniors over 80 is projected to nearly double between 2012 and 2036 (British Columbia Ministry of Health, 2013). This increasing number of seniors is followed by increases in the likelihood of acquiring chronic illness, including cancer, or co-morbidities, as well as a longer life on medications (Flesner, 2004; Stajduhar, 2013). Bastawrous (2013) noted that seniors that are 65 years or older represent 15%, 12.8%, and 17.1% of the Canadian, American and European populations, respectively, and in Canada, the centenarians have been the fastest growing age group, with a growth rate of 25.7% between 2006 and 2011 (Statistics Canada, 2012). The 2011 Canadian census enumerated 5,825 centenarians and it is predicted that by 2031, that number will increase to more than 17,000 (Statistics Canada, 2012). With this significant growth in the aging population, increases in life-limiting illnesses are also inevitably on the rise.
2.2.2 Cancer is on the rise

The number of people living with specific illnesses such as cancer are projected to dramatically increase in the future (Chapelle & Hollander, 2011; Denton & Spencer, 2010; Ellison & Wilkins, 2012; Garrett & Martini, 2007; Montague, 2009). In 2013 alone, approximately 187,600 new cases of cancer were diagnosed in Canada and 88% of Canadians who developed cancer were over the age of 50 (Canadian Cancer Society, 2013). This suggests that one of the most important contributing factors to the growth of cancer incidence in Canada is the aging population (Ellison & Wilkins, 2012). The Canadian Cancer Society (2013) noted that the annual incidence increase is an important measure of cancer burden on the Canadian population and health care system, and such information is essential when planning for adequate services for current and future health care. In light of the aging population and its correlation to increased life-limiting illnesses, a dramatic increase in the number of deaths is expected.

2.2.3 Increased number of deaths

Though the increase or decrease of mortality rates for different types of cancer vary, the number of deaths from cancer per year in Canada has increased steadily since 1984, and the trend is predicted to continue (Canadian Cancer Society, 2013). In 2013, an estimated 75,500 Canadians died of cancer (Canadian Cancer Society, 2013). Of these deaths, 95% occurred in people over the age of 50, and most of these cancer deaths (61%) occurred in those aged 70 and over (Canadian Cancer Society, 2013). Needless to say, with an aging population, and associated increases in life-limiting illness (cancer in particular) and death, there exists an increased need for care and for families to provide that care.
2.2.4 Demands on the health care system for care

Increases in disease and death have had an inevitable impact on the health care system in Canada, and have contributed to concerns regarding health care sustainability (Chapelle & Hollander, 2011; Montague, 2009; Sarma, Hawley, & Basu, 2009; Wilson et al., 2005). A shift has occurred to move health care for individuals into the community, and in many cases for care to be provided by family members (Crooks et al., 2012; Guerriere et al., 2010; Stajduhar, 2013). In some cases this shift was due to substantial hospital downsizing in response to economic constraints and health reform that was aimed toward minimizing government costs. In response, critics have suggested that the provision of home care has been “offloaded to families” (Stajduhar & Davies, 1998; Wilson et al., 2005), who are often ill prepared for this role.

Through the lens of minimizing government costs, Stajduhar and Davies (1998) highlighted the cost-effectiveness of a home death in lieu of the costly institutionalized alternative (see also Wiles, Leibing, Guberman, Reeve, & Allen, 2011). The closure of acute care hospital beds was one factor that has been associated with the development of home-based palliative care services, because home death offered a strong economic argument compared to death in hospital (Stajduhar & Davies, 1998). For instance, evidence suggests that with palliative hospitalizations there is a pronounced rise in annual health care costs in the final years of life, which can account for approximately 10% of lifetime health care costs (Caley & Sidhu, 2011). Hopes of minimizing these expensive hospitalizations further supported the push for family members to provide care at home during the end stages of life.

2.2.5 Preference to live and die at home

A driving force for living and dying at home comes from the patients themselves and is
facilitated by FCGs’ support. Care at home is generally viewed by the general public as optimal for individuals with advanced illness (Edwards et al., 2012; Hudson & Payne, 2011; Stajduhar, 2013; Topf et al., 2013), and is often held as a “gold standard” for palliative and end-of-life care (Stajduhar & Davies, 1998). The Canadian Institute for Health Information (2011) reported that 87% of Canadians aged 55 or older want to live at home for as long as possible, and a similar percentage expressed a preference for dying at home (Stajduhar & Davies, 2005). Indeed, more than 90% of Canadians would like to die in their homes, yet 75% of expected deaths in Canada have occurred in hospital or residential care (Canadian Hospice Palliative Care Association, 2012).

There are a number of factors underlying trends related to the provision of care to enable dying at home. A major factor supporting palliative care at home is the belief that death at home contributes to the overall quality of life of patients and families (Wiles et al., 2011). It is widely accepted that dying in the home environment facilitates a sense of normalcy, which offers security to those who are dying (Stajduhar & Davies, 2005; Wiles et al., 2011). Care at home is further associated with freedom and control because patients can usually rise, bathe, dress, and eat according to their own schedule rather than having to conform to the hospital’s routine. One study found that the home environment also helped facilitate relationships with family and friends despite a regularly shifting and unpredictable situation (Stajduhar & Davies, 1998). Moreover, several scholars state that dying at home contributes significantly to the overall well-being of patients and often the families as well (Stajduhar & Davies, 1998; Wang, Shepley, & Rodiek, 2012). However, research also shows that palliation does not always progress in a foreseeable manner, and often requires increased supports, technology and expertise to keep the patient as comfortable as possible, which may
not be available in the home (Stajduhar & Davies, 1998; Topf et al., 2013). The inability to meet these requirements can prevent a home death or the home death may not offer the dignity and comfort once imagined. Therefore, though the goal might be for a home death, it might not be possible or the best option at end-of-life, and more suitable options must be presented to FCGs, along with permission to change their mind (Stajduhar et al., 2011; Topf, 2012).

2.2.6 FCGs required to provide care at home

In cases where a home death is desired, it usually does not happen effortlessly as ideals of ‘passing away in our sleep’ would suggest, but rather requires significant management and support. Research shows that both FCGs and home care nursing and support services are required to effectively support care at home (and death where desired), yet the latter can be difficult to access in Canada (Stajduhar et al., 2010), and in many instances is suboptimal (Hudson & Payne, 2011; Robinson et al., 2012; Topf et al. 2013). There is no question that FCGs are vital to the health care system, as they provide the majority of physical and emotional care for individuals with life-limiting illnesses, particularly those who wish to die at home (Funk et al., 2010). FCGs are crucial in supporting family members in their desire to remain at home (Funk et al., 2010; Henriksson & Arestedt, 2013; Hudson & Payne, 2011; Stajduhar & Davies, 2005). Further, research findings indicate that family members are willing to provide the care that is required. An estimated 8.1 million Canadians over the age of 15 have provided care to individuals at home with chronic health conditions or life-limiting illnesses (Sinha, 2013). It is predicted that by 2031, the need for caregivers will double (Social Sciences and Humanities Research Council, 2012). Further, research indicates that fewer people are able to die at home than would wish to, due to a lack of FCGs or lack of
appropriate support for their FCGs (Topf et al., 2013; Wilson, 2000).

2.3 Experiences of Palliative Caregiving

In this section, the literature describing family palliative caregivers’ experiences is summarized to give a better understanding of the support they require.

2.3.1 FCGs’ desire to provide care

The literature shows that FCGs want to provide care for their family members with an advanced life-limiting illness (Edwards et al., 2012; Funk et al., 2010; Robinson et al., 2012; Topf et al., 2013). Despite the challenges that FCGs experience in their role, researchers report that providing care had great purpose and meaning for FCGs (Blum & Sherman, 2010; Funk et al., 2010; Robinson et al., 2012). FCGs report being satisfied with providing care for their family member, which often fulfilled a priority request of their family member. Furthermore, caregiving offered the satisfaction of time together, and the opportunity to have provided as much normalcy as possible by remaining at home (Collins & Swartz, 2011). In one study, researchers documented caregiver strengths such as: "balance, coping, emotional resources, personal strength, positive outcomes, meaning, and spiritual gifts" (Hogstel, Curry, & Walker, 2005, p.55). Furthermore, women reported gain, reward, or beneficial effects from the caregiving role, and these "women report[ed] greater life-purpose, autonomy, personal growth, and self-acceptance than their non-caregiving peers" (Hogstel et al., 2005, p.55). Whether burdensome, beneficial, or both, there is evidence that FCGs assume the caregiving role, even when there is a lack of appropriate supports as well as personal and financial costs (Robinson et al., 2012; Stajduhar, 2013).

2.3.2 FCGs are unprepared and unsupported

The findings of recent studies indicate that despite FCGs’ common desire to provide
care for their family member, most experienced being unprepared to provide the required care, which meant they lacked the necessary knowledge and skills (Årestedt & Henriksson, 2013; Bialon & Coke, 2012; Funk et al., 2010; Robinson et al., 2012). Indeed, FCGs are increasingly being engaged in the delivery of complex and unfamiliar care (Aoun, Kristjanson, Currow, & Hudson, 2005). Palliative home care puts FCGs in the situation where they need to “quickly learn” how to provide nursing care (Redinbaugh et al., 2003). Robinson et al. (2012) referred to this phenomenon as becoming a “mini-nurse.” This steep learning curve causes high levels of stress in many caregivers as well as feelings of fear, isolation and responsibility for unfamiliar care (Redinbaugh et al., 2003; Robinson et al., 2012). In the study conducted by Robinson et al. with rural dwelling FCGs in British Columbia, FCGs were found to have little to no training, limited access to formal support, and were often left to learn as they went, which occasionally meant learning through mistakes. Their responsibilities included the management of gastric tubes and feeds, physiotherapy, extensive medication regimens, including subcutaneous opioid administration, as well as the gathering of necessary equipment for care (Robinson et al., 2012). Others have also reported that FCGs often face a lack of needed formal support (Funk et al., 2010; Topf, 2012). Overall, there is accumulating evidence that FCGs feel unprepared and unsupported, and lack important knowledge, skills and supports to manage care (Årestedt & Henriksson, 2013; Bialon & Coke, 2012; Funk et al., 2010; Hudson & Payne, 2011; Redinbaugh et al., 2003; Robinson et al., 2012; Topf et al., 2013).

2.3.3 Consequences of family caregiving

The consequences of family caregiving for FCGs are varied and related to a number of factors. Despite the necessity of FCGs to provide care at home, family members may be
ambivalent about becoming FCGs, but often feel they have little choice (Stajduhar & Davies, 2005; Topf et al., 2013). For example, in Canada, a national survey on FCGs determined that over 50% of caregivers believed that no choice existed in caring for their palliative family member (Stajduhar & Davies, 2005). Such FCGs often provided care based on the wishes of their palliative family member (Aoun et al., 2005; Stajduhar & Davies, 2005). Robinson et al.’s (2012) study reported that the acceptance of the role was “simply taken-for-granted” (p.473), which is supported by Topf (2012) who found that there was no explicit conversation or decision making regarding the caregiving role. The factors involved in taking up a caregiving role, therefore, can have important consequences for FCGs. While many FCGs value their caregiving role and report a sense of fulfillment, it is not without significant sacrifice (Stajduhar, 2013). The burden on FCGs is well documented and is associated with physical, psychosocial, and financial strains (Aoun et al., 2005; Bastawrous, 2013; Funk & Stajduhar, 2009; Guerriere et al., 2010; Bialon & Coke, 2012; Robinson et al., 2012; Stajduhar, 2013).

2.3.4 Physical consequences of caregiving

FCGs commonly experience chronic fatigue, physical exhaustion, difficulty sleeping, burnout, and deterioration of their own health when caring for dying family members (Aoun et al., 2005; Bastawrous, 2013; Bialon & Coke, 2011; Hearson, McClement, McMillan & Harlos, 2011; Stajduhar, 2013). These consequences are the result of a diverse and demanding workload including assisting with personal activities of daily living (ADL; e.g., bathing, dressing, grooming, eating, toileting, transferring) as well as instrumental activities of daily living (IADLI; e.g., transportation, grocery shopping, housework, managing finances, and preparing meals; Hebert & Schultz, 2006). Furthermore, FCGs often administer
medications, which include complex non-oral medications such as injections, in order to manage their family member’s pain and overall health needs (Hebert & Schultz, 2006). In one study it was reported that over one-half of FCGs have at least one chronic condition, which was often exacerbated due to the stress and sleeplessness they experienced when caring for family members who were dying (Collins & Swartz, 2011). Caregivers have also been found to be at greater risk for serious illness, and they were less likely to seek preventive treatment; they often neglected or minimized their own needs because they did not want to take time away from their seriously ill family member (Edwards et al., 2012; Funk & Stajduhar, 2009; Hebert & Schultz, 2006; Rabow, Hausser, & Adams, 2004; Robinson et al., 2012). Furthermore, older spousal caregivers who experienced stress from caregiving were more likely to experience an early death than non-caregivers (Aoun et al., 2005).

2.3.5 Psychosocial consequences of caregiving

In addition to physical morbidity, there is evidence that FCGs were also at risk for psychological morbidity (Blum & Sherman, 2010; Hudson & Payne, 2011). Rabow, Hauser, and Adams (2004) found that although many FCGs carried a deep sense of purpose and fulfillment in this role, this was accompanied by feelings of sadness, guilt, and exhaustion. Researchers reported that in the year before death the prevalence of anxiety in FCGs was as high as 46% and that depression rates were between 40-60% (Aoun et al., 2005; Rabow et al., 2004). They argued that these rates of anxiety and depression stemmed from the high levels of stress involved in providing care, which were further exacerbated by feeling ill equipped, isolated and restricted in time and freedom (Aoun et al., 2005; Rabow et al., 2004; Stajduhar, 2013). Others noted that psychosocial consequences of caregiving stemmed from
disruptions to personal routines and leisure activities that might have otherwise helped mediate stress, and role conflicts associated with balancing the needs of the ill family member with those who were well (Stajduhar, 2013; Stajduhar & Davies, 1998).

### 2.3.6 Financial consequences of caregiving

Family caregiving comes at a great financial cost to most individuals and families (Aoun et al., 2005; Guerriere et al., 2010; Hudson & Payne, 2011; Rabow et al., 2004; Stajduhar & Davies, 1998). In several studies, many caregivers were found to experience a loss of income and benefits due to time away from work to perform caregiving duties, while 20% of caregivers had to quit work or make major life changes (Rabow, et al., 2004; Stajduhar, 2013; Stajduhar & Davies, 1998). In Canada, an estimated 1.5-2 million FCGs provide care valued at 25-26 billion dollars annually while sustaining 80 million dollars of annual out-of-pocket expenses (Williams & Crooks, 2010). Even with a publically funded health care system as in Canada, families are often responsible for purchasing medications and home care supplies, for renting equipment and for paying for transportation and respite services (Aoun et al., 2005; Guerriere et al., 2010). Guerriere et al. (2010) further calculated the financial cost to palliative FCGs by measuring the cost of caregivers’ time dedicated to caregiving, which included time lost from the labor market and from household work.

Moreover, as Collins & Swartz (2011) reported, female caregivers were at even greater risk financially than men, because females who provided care for their parents were 2.5 times more likely to live below the poverty line.

Health reforms have moved long-term and palliative care into the community, and more specifically into individuals’ homes, which has off-loaded the cost (Guerriere et al., 2010; Stajduhar, 2013). Yet, researchers claim that health care systems remain largely
unresponsive to the needs of FCGs (Aoun et al., 2005; Hudson & Payne, 2011; Stajduhar, 2003), which leaves some caregivers with the experience or belief that they have been exploited by the health care system (Stajduhar, 2003). Such financial strains highlight the lack of support that FCGs often experience.

In summary, FCGs report that they want to provide care at home for their palliative family members despite the fact they feel they have little choice. Further, FCGs often feel unprepared and unsupported in their role. In relation to FCGs’ lack of preparedness and support, as well as the diverse and demanding workload included in caregiving, palliative FCGs often experience physical, psychosocial and financial consequences. Due to these consequences, FCGs are often challenged in their ability to maintain caring at home and therefore require support.

### 2.4 Support Required

Given that FCGs generally desire to provide care for their family members for as long as possible, and that the current trends in our health care system require them to provide such care, FCGs need increased support to successfully continue in their role (Hudson & Payne, 2011; Stajduhar, 2013). The World Health Organization (2013) stated that “palliative care is an approach that improves the quality of life of patients and their families [emphasis added] facing the problem[s] associated with life-threatening illness” (para.1). In order for the palliative approach to effectively address the quality of life for patients and their families, increased support is essential for FCGs; yet it is unclear how best to achieve such support (Aoun et al., 2005). There is an international call to develop interventions for FCGs.

Early intervention is a recommended method to help caregivers recognize potential difficulties that require further support, or may render care at home unrealistic or even
impossible. Furthermore, research shows that FCGs require the knowledge that options for care are available and changes are sometimes necessary (Topf et al., 2013). Several scholars found that early understanding and dialogue about this possibility might have served caregivers well in minimizing the guilt they felt if or when they made changes to their family members’ care arrangements (Funk & Stajduhar, 2009; Topf et al., 2013). Because care needs can change drastically over the course of a family member’s illness trajectory, and FCGs are often unaware of their options, and require support in decision making (Topf et al., 2013), a re-evaluation of and flexibility in the dying person’s living arrangements and care needs may be helpful in supporting FCGs.

### 2.5 Decision Support Guides

Information, options, and discussions are required to provide ill persons and their family members with the tools and supports they need (Neuman et al., 2007; Topf, 2012). Decision support is a key element of this service (Burman et al., 2013). Decision support tools include decision aids, which have gained favour in their use and have been described as one of the most important health communication innovations of the past decade (Elwyn et al., 2006). In addition to medical counsel, patient decision aids are used to explain options, help clarify personal values, and guide patients in reflection and communication (Morris, Drake, Saarimaki, Bennett, & O’Connor, 2008). The findings of two systematic reviews provide evidence that decision aids improved participation in decision making (Durand et al., 2014; Stacey et al., 2014), “improve[d] people’s knowledge regarding options, and reduce[d] their decisional conflict related to feeling uninformed and unclear about their personal values” (Stacey et al., 2014, p. 3). Further, decision aids have been demonstrated to improve patient-practitioner communication (Stacey et al., 2014). Decision aids are often comprised of visual
representations, which summarize the pertinent information, and thus reduce cognitive overload during decision making and ensure patients’ decisions are made on complete information rather than assumptions or biased information (Bekker, Hewison, & Thorton, 2003). Decision aids allow patients time to consider relevant, evidence-based content in conjunction with personal values and preferences by strategically working through vital topics outlined in the decision aid. Thus, the decision aid functions as a starting point for an authentic conversation of complex issues both between patient and family and families and clinicians (Burman et al., 2013).

An effective decision aid has the potential to equip FCGs with the tools to navigate this rewarding, yet difficult caregiving journey. A critical component to the development of an effective tool is the presentation of complex information in a manner that patients and caregivers can understand and find relevant to their situation (Burman, et al., 2013).

Decision aids can have an important influence on the choices people make, therefore, developers must be cautious to avoid bias and hence are encouraged to follow recognized methods. Particularly with the growing global interest in decision aid development, it is important that standards be in place to ensure the quality and safety of decision aids, and encourage the use of science to underpin the design, development and methods (Elwyn & O’Connor, 2009). The International Patient Decision Aids Standards (IPDAS) Collaboration was established in 2003 in response to the need for internationally accepted standards to assess the quality and potential biases of guides. IPDAS developed an international consensus-based framework of quality criteria that serve as a guide for developers and users of decision aids. The final quality framework included the following development standards: (1) use of a systematic development process; (2) provision of information about options; (3)
presentation of probabilities; (4) values clarified and expressed; (5) use of patient stories; (6) guiding or coaching of deliberation and communication; (7) disclosure of conflicts of interest; (8) delivery of patient decision aid on the internet; (9) balanced presentation of options; (10) use of plain language; (11) information based on up-to-date scientific evidence; and (12) effectiveness established (Elwyn et al., 2006). Though the IPDAS checklist is thorough in creating quality standards, its goal is not to provide precise, quantitative assessments or judgments about the quality of individual guides; not all checklist items are applicable to every decision aid.

It is important to note that a decision guide in this context is different than traditional tools called decision aids, which support a specific singular decision (person comes to a decision they can live with when there is no clear right or wrong answer). For FCGs, the process involves a series of decisions, and decisions may be re-visiteded with different outcomes later in the illness trajectory.

2.6 Summary

In summary, the context of family caregiving has been shaped by multiple factors, which have increased the need for FCGs to care for their family members in the home. The experiences of FCGs who have provided such care demonstrate the need for increased support for FCGs. I presented the literature in the following manner to support my argument:

1. Demographic shift
2. Aging population
3. Increased chronic illness including cancer
4. Rising death rates
5. Health care system changes
6. Patient preference to live and die at home
7. FCGs are required to provide care at home
8. FCGs desire to provide care at home
9. FCGs are often unprepared and unsupported
10. Consequences of caregiving to FCGs

These points all lead to an increased need for FCGs who require support, yet there is little understanding about what support is necessary and how best to provide it.
Chapter 3. RESEARCH METHODS

3.1 Study Purpose and Objectives

The growing evidence regarding the experiences of family palliative caregivers has highlighted the need for effective support interventions (e.g., Funk et al., 2009; Hudson et al., 2004; Robinson et al., 2012; Topf et al., 2013). It is also apparent that supporting FCGs can be challenging because they resist a shift in focus to them and their needs. However, we know enough about family caregiving to know that interventions need to prepare them to be the best possible caregivers. An intervention that focuses on educating and helping FCGs anticipate future caregiving needs, and make repeated decisions over time that are in accord with their values, beliefs and preferences may therefore be beneficial. Based on this understanding, and the success of decision aids in supporting decision making as well as the accessibility of international standards for the development of decision aids, the FCGDG was constructed. The next step was to evaluate its comprehensiveness, understandability, applicability, and usefulness to FCGs. Hence, the aim of this qualitative description study was to field test and further refine the FCGDG with a focus on enhancing acceptability, understandability, and applicability. A qualitative approach to the evaluation of the FCGDG allowed for the subjective experiences of the participants to be heard (Thorne, 2010) and to shape this tool. A second evaluation study is planned and will focus on effectiveness in practice.

The study was designed in two separate phases using a qualitative description approach (Sandelowski, 2000, 2010). In phase one, we conducted focus groups with bereaved FCGs. In phase two, we conducted individual interviews with current FCGs using cognitive interviewing techniques. Following each phase, the data from FCGs were analyzed
and used to modify the FCGDG with the aim of enhancing its usefulness. The use of two phases allowed the research team to address problematic areas of the guide identified in phase one, and to refine it prior to further testing.

3.2 Phase One: Study Design

This initial phase of the research used focus groups to evaluate the FCGDG. Focus groups were conducted in the south central region of British Columbia (BC), and study sites included hospices and the local BC Cancer Agency.

3.2.1 Sample

We used convenience sampling to recruit bereaved FCGs who had cared at home for a family member with advanced cancer. Inclusion criteria were as follows: bereaved individuals who provided care to a family member with advanced cancer at home and who could speak, read and write English, and were 18 years of age or older. FCGs could include spouses, partners, parents, siblings, adult children, or individuals designated as a family member by the palliative individual, such as a close friend. Non-English speaking and formal caregivers (i.e., paid health care providers) were excluded from the study. The research team recruited bereaved FCGs in the first phase of the research to avoid potential over burdening of current FCGs with a guide that had not yet been refined.

Recruitment occurred in two ways. 1. We notified potential participants of the study through recruitment bulletins (Appendix A), which were distributed through email and through volunteer coordinators at the BC Cancer Agency and hospices. Interested individuals then received a consent-to-contact form (Appendix B). Once a consent-to-contact was signed, a member of the research team followed-up with the individual to screen them for eligibility to participate, to explain the study in more detail (i.e., confidentiality, consent,
time, and location of the group) and to answer any questions the participant might have had.

2. Members of the research team contacted participants from a previous study (Topf, 2012) who had consented to being contacted with information regarding new studies (Appendix C). A letter of consent was then sent out by mail or email to those who wished to participate (Appendix D). All interested participants provided written informed consent after having at least 24 hours to consider participating in the study.

3.2.2 Data collection

Focus group methodology, sometimes referred to as a group interview, distinctively combines elements of group dynamics and qualitative research methods to generate cost-effective, quality information (Morrison & Peoples, 1999). The design of focus groups help obtain participants’ feelings, perceptions, and opinions regarding a specific problem, experience, tool, or service, in a respectful environment (Morrison & Peoples, 1999). This qualitative method gained popularity with nursing researchers due to its relative ease and broad range of applications (Sharts-Hopko, 2001). Furthermore, this method is considered highly appropriate for use in product development, pre-testing and formative evaluation, which demonstrates the rationale for its use in this study (Krueger & Casey, 2000).

The research team collected data from three focus groups, which consisted of 4-8 participants each (Magilvy & Thomas, 2009). We conducted focus groups in a private room in either the local hospice or cancer center, which offered the participants a confidential, accessible and potentially familiar location for their discussion. Further, refreshments and chairs in a circular pattern offered a relaxing, informal setting to facilitate open dialogue. Each focus group lasted approximately two hours.
Participants began by completing a demographic form (Appendix E). We then asked them to review the decision guide independently and discuss it in the focus group. A member of the research team facilitated the group discussion to obtain feedback from the participants and the discussion was audio recorded.

In order to facilitate maximum participation in the focus groups, it was important to create an informal, neutral environment, where a non-judgmental and open atmosphere could be established (Litosseliti, 2003). To set this tone, the group facilitator welcomed the participants, thanked them for their time, and emphasized that all perspectives were valued. Expectations were clarified: we encouraged participants to speak freely, to discount reaching consensus, to take turns speaking, and assured them that no opinions were right or wrong (Litosseliti, 2003). The facilitator further emphasized her role: to listen, to keep the conversation on track, and to ensure that everyone’s ideas were heard.

The group facilitator guided the discussion using broad, open-ended, questions about the decision guide (Appendix F). When open-ended questions did not provide the desired depth of information, the interviewer used probes to encourage participants to expand on or clarify their comments. The facilitator was mindful of the group dynamics, and addressed issues with dominant, shy or rambling participants, as well as recognized the social influences on self-disclosure (Fern, 2001). The interview process invited participants to contribute to the development of the FCGDG by providing suggestions to enhance the guide. In addition to the audio-recording, a member of the research team took detailed field notes of the discussion.
3.2.3 Data analysis

Consistent with a qualitative descriptive approach, I conducted an inductively driven content analysis of the focus group data (Sandelowski, 2000). Qualitative content analysis is "a dynamic form of analysis of verbal and visual data that is oriented towards summarizing the informational contents of that data" (Sandelowski, 2000, p.338). The data from this study was relatively concrete, and provided specific guidance for the FCGDG modifications. The content approach, based on the “factist” perspective, assumed data to be generally accurate and truthful indexes of the reality that existed (Sandelowski, 2010; Vaismoradi, Turunen, & Bondas, 2013). This method was fitting for the current research, because the study was pragmatic and was aimed at gaining the truthful perspectives of FCGs regarding the FCGDG’s usefulness in light of their past experiences with caregiving. In this study “straight descriptions of the phenomena [were] desired” (Sandelowski, 2000, p. 339).

I listened carefully to the focus group audio-recordings, took detailed notes, and read and re-read the notes. After becoming familiar with the data, I recorded specific data pertaining to the development of the guide onto a data analysis table organized under the research questions. As described by others (Graneheim & Lundman, 2004; Vaismoradi et al., 2013), coding focused on the identification of important or interesting features of the data related to the research questions, and the organization of the data into meaningful groups. Staying close to what participants said about the FCGDG, I then created descriptive categories as a way to group similar FCG responses to and suggestions regarding the FCGDG. Team meetings facilitated the organization of emerging categories through investigator triangulation, and these discussions prompted reflections on components of the FCGDG that were recorded and also included in the process of data analysis. The data were
coded into the following categories: images and charts, language, content, readability/comprehension, and sequencing/layout/design of the guide. Finally, summaries of the data related to each of the categories were developed to provide direction for refinement of the FCGDG (Sandelowski, 2000). The research team further discussed potential sampling issues, and the development of questions to be included in subsequent interviews. The FCGDG was substantially revised prior to Phase two.

3.3 Phase Two: Study Design

In the second phase of this qualitative description study, cognitive interviewing was incorporated to evaluate the revised FCGDG with a convenience sample of FCGs who were currently engaged in caregiving. The rationale for the use of cognitive interviewing was its emerging prominence as a method to identify and correct problems within research tools or guides (Beatty & Willis, 2007). Using this data collection method allowed for the collection of additional verbal information while participants responded to sections of the guide. The research team then used this information from the second phase of our ‘field test’ to evaluate the understandability, applicability, and usability of the FCGDG (Beatty & Willis, 2007).

3.3.1 Sample

Inclusion criteria to participate in the second phase of this study were as follows: individuals who were currently providing care to a family member with advanced cancer at home, were 18 years of age or older and who could speak, read and write in English. FCGs could include spouses, adult children, siblings, or individuals designated as a family member by the palliative individual. Non-English speaking and formal caregivers (i.e., health care providers) were excluded from the study.
We used multiple techniques to recruit participants, including the distribution of flyers (Appendix G), a media release, personal contacts, and the assistance of health care professionals. Staff at the Sindi Ahluwalia Hawkins Centre for the Southern Interior (SAHCSI), BC Cancer Agency assisted in recruiting family caregivers who accompanied people with advanced cancer when they attended the pain and symptom management clinic or patient and family counseling. Health care providers introduced the study to the FCG, and gave them an information sheet about the study that included my contact information (Appendix H). Interested FCGs were asked to contact me directly. Nurses from the Central Okanagan palliative program further assisted with recruitment. The research team also provided nurses with an information sheet (Appendix H) to give to current FCGs with the researcher's contact information on it. The nurses briefly introduced the study to FCGs of someone with advanced cancer and then offered the information sheet. Participants would then self-refer to the study if interested. Alternatively the nurses could give the current FCG the Information Sheet and Consent to Contact form (Appendix I). Interested FCGs could sign the Consent to Contact and the nurses would then give this information to the researcher who arranged a suitable time to speak to or meet with the FCG to provide them with more information and the opportunity to participate in the study.

Interested individuals contacted me and I explained the study in more detail (i.e. confidentiality, consent, time, and location of the interview) and answered any questions. Eligible current FCGs who wished to participate were then sent a letter of consent by mail or email (Appendix J). All participants provided written informed consent after having at least 24 hours to consider participating in the study. If families from Central Okanagan Hospice House wished to be interviewed immediately when the researcher contacted them with more
information (considering the time sensitivity of their family member’s condition), they did not have 24 hours to review the consent form. I collected signed consent forms via email or in person at the time of the interview.

3.3.2 Data collection

3.3.2.1 Cognitive interviewing. In an interdisciplinary effort, survey methodologists and psychologists developed cognitive interviewing in the 1980s (Willis, 1999). Cognitive interviewing focuses mainly on the questionnaire, or in this case the guide, rather than its administration process; it is the cognitive process participants engage in when reviewing the guide that is of particular interest rather than the answers to the guide or questionnaire itself. Cognitive interviewing is based on cognitive theory, which has been represented by various models. The most prevalent model is attributed to Tourangeau (1984, as cited by Willis, 1999). Tourangeau depicted a cognitive interview as consisting of four main processes: comprehension of the question, retrieval from memory of relevant information, decision processes, and response processes. In the evaluation of the FCGDG, the “think aloud” and verbal probing approaches to cognitive interviewing were used concurrently to facilitate these processes and maximize results. I used “think aloud” methods throughout the entire administration of the FCGDG, whereas I used verbal probing in areas that had been identified through the focus groups as potentially problematic or where elaboration was desired.

3.3.2.2 “Think-Aloud” interviewing. The “think-aloud” interview originated from psychological procedures by Ericsson and Simon (1980; as cited in Willis, 1999). The term “describes a very specific type of activity, in which subjects are explicitly instructed to “think aloud” as they answer the...questions” (Willis, 1999, p.3). In this study, participants were
instructed to “think aloud” as they viewed the FCGDG page by page and their responses were both audio-recorded and briefly recorded in writing. The intent was to obtain participants’ candid thoughts on readability, comprehension, and content. I sometimes asked the participant what they were thinking when they paused, however interjected little else.

As the participant was likely new to this style of interview experience, it was important to teach them how to perform the “think-aloud” procedure. In order to practice this method, I asked participants to look at the cover of the FCGDG and to share their immediate impressions (Willis, 1999). Once participants were comfortable with the “think aloud” method, the actual interview began.

3.3.2.3 Verbal probing. An additional method to the “think-aloud” method was the basic technique of verbal probing. After I asked the question, and the participant answered, I asked for further, more specific information relevant to the question or answer given; basically “probing” the participant for their thoughts regarding the particular question or response (Willis, 1999). I used verbal probing in areas that had been identified through the focus groups as potentially problematic or where elaboration was desired.

3.3.2.4 Interview process. In the second phase, I conducted one-on-one cognitive interviews with current FCGs. One interview was conducted per participant. Interviews were conducted in a comfortable and private meeting place convenient to the participant, either in the participant’s home, or a private room at the local hospice. The interviews took between an hour and two hours of participants’ time.

Demographic data was collected from each participant (Appendix K). I aimed to establish a safe and respectful environment and therefore welcomed the participant, thanked them for their time, ensured them of confidentiality and emphasized that their perspective
and expertise were valued. Expectations were clarified and participants were encouraged to speak freely. I further reassured participants that no opinions were right or wrong. Once participants were settled, I began with a pre-interview preparation to familiarize the participants with the “think-aloud” process. To ensure that all data was recorded, I took notes on participants’ feedback and audio recorded the discussions.

After the pre-interview preparation was complete, the participants reviewed the remainder of the guide in the following manner: they completed one page at a time, while sharing their reflections as they did so. At the conclusion of each page I asked five questions: What did you like about this page? What didn’t you like about this page? What was not clear or understandable to you? How might this have been useful/helpful? What was not helpful? If the participant identified problematic areas of the guide, or if we were concerned about potentially problematic areas (e.g. sensitive language) based on the phase one, verbal probing was used. In accordance with IPDAS (Elwyn & O’Connor, 2009), I asked general questions at the conclusion of the guide, such as: (1) How did you experience the guide overall? (2) Thinking back, could you easily read and understand the guide? (3) Did you feel it influenced you in any particular direction around your family caregiving? (4) Overall, how useful might it be for your caregiving situation? (5) Did the guide identify important decisions and would it help you make those decisions? If participants gave yes/no answers to the preceding questions, I further explored the answers to more fully understand their responses. These questions helped to address the ultimate goal of this pilot study, which was to improve the quality and utility of the guide in order to help FCGs make decisions related to providing end-of-life care, prior to using the FCGDG in future studies.
3.3.3 Data analysis

In addition to the audio recording of the interview, participants’ responses were recorded directly onto a copy of the FCGDG. Written notes from the cognitive interviews were typed up following the interviews and were expanded upon with the use of audio recordings. I reviewed each audio recording and recorded specific data about the development of the guide onto a data analysis table organized under questions or pages from the FCGDG. I reviewed the data to develop descriptive categories in a similar manner to phase one of the research. Team meetings facilitated the organization of emerging categories through investigator triangulation. Team members’ discussions of the data also prompted further reflections on components of the FCGDG, and these reflections were also recorded and included in the process of data analysis. The data were coded using the following categories: images, language, content, readability/comprehension, and sequencing/layout/design.

Methodological rigour throughout phases one and two were achieved in several ways. The research team integrated verification strategies throughout the research process. Focus groups and interviews provided opportunities for clarification of data and beginning analysis. Opportunities for thorough and complete analysis were offered through multiple sources of data (i.e. focus groups and cognitive interviews) and analytical method (content analysis). An audit trail was kept to record procedures, decisions, possible theme development, and sources of bias.

3.4 Ethical Considerations

In this section, I discuss the ethical considerations for both phases one and two of the research. The research team obtained ethics approval for this qualitative study from both the
University of British Columbia Okanagan’s Behavioural Research Ethics Board and the Interior Health Research Ethics Board.

I prepared for the ethical aspects of this research through the completion of the Tri-Council Policy Statement (TCPS) Tutorial. The core principles of the TCPS are: respect for persons, concern for welfare, and justice (TCPS, 2010). These principles guided the conduct of this research.

This study included current and bereaved FCGs and required their feedback on the FCGDG. Concern for burden on current FCGs led to their later involvement (phase two) once there had been an indication of the potential usefulness of the guide. With both bereaved and current FCGs, it remained possible that FCGs’ reflection on their caregiving experiences may have induced distressing emotional responses. Though no participants became overly distressed, a few became tearful, at which point I briefly paused the interview to allow the participant space to process emotions. However, all participants desired to quickly continue with the interview and a couple commented how the sharing process had been beneficial for them.

The research team kept participants’ identity and discussions strictly confidential; however, the nature of focus groups cannot guarantee absolute confidentiality because other participants in the group were present for the conversation. We requested that participants respect the privacy of the other group members by not revealing their identities or disclosing what was discussed in the group with others. Nevertheless, we could not guarantee participants’ respect of this request. The research team informed participants of these limitations of confidentiality via consent forms and verbally at the commencement of the focus group discussions. Furthermore, we removed all personal identifiers from the data. All
data records were stored at UBC Okanagan in a locked, secure location and electronic files were password-protected. Upon completion of the study, information from the study will be kept electronically according to UBC Okanagan policies for a minimum of 5 years, and all hard copies will be permanently destroyed. Access to the participants’ data was and will be restricted to the research team and project coordinator, all of whom are trained in the proper handling and storage methods of confidential data.
Chapter 4. FINDINGS

4.1 Overview

In this chapter I will present findings obtained from this evaluation of the FCGDG, which focus specifically on its general usefulness and understandability. Data acquired in this study reflects the perspectives and experiences of family caregivers who cared for, or are currently caring for, family members with advanced cancer. This study was conducted in two phases; this chapter presents the findings that correspond to each phase. In the first phase, the research team conducted three focus groups with bereaved FCGs (total n=14). In the second phase, a member of the research team conducted cognitive interviews with eight current family caregivers. This chapter presents participants’ responses in five categories, including their perspectives on the images and charts, language, content, readability/comprehension, and sequencing/layout/design of the guide. (For a comprehensive view of the data, please see appendices L and M.). In addition, the research team’s reflections on the findings and conclusions about needed revisions are presented.

4.2 Phase One

4.2.1 Description of the sample

The three focus groups consisted of 14 bereaved family caregivers. The sample included 11 (79%) women and three (21%) men. The mean age of the participants was 78, with one participant omitting their age from the demographic data. The caregivers’ relationship to the care recipient included spouses, siblings, parents, children, and a friend. Eleven of the 14 participants were not employed or were retired, while one described their employment as part-time, one as full-time, and one as self-employed. Bereaved caregivers were a more accessible population because they were not currently caring for a family
member, yet possessed the experience of caregiving at home and could speak to the guide’s relevance, usefulness, and understandability.

4.2.2 Charts and images

In this first phase of the research we presented family caregivers with a version of the guide that did not contain images. The lack of images combined with the complexity of many charts contributed to an initial feeling of burden and confusion for many participants, who compared the guide to an “income-tax form.” Participants described the overwhelming amount of paper work they faced during the experience of caregiving. They explained that, despite the helpful intention of the guide, it would not be received as such if it maintained its “raw format.” Participants suggested that the addition of warm or compassionate images would “soften” the FCGDG, making it more inviting. Further, they indicated it would show sensitivity to the difficulty of the caregiving situation.

Several tables and charts existed in the original version of the FCGDG presented to the focus groups. Participants found the information in the tables useful but found the tables themselves confusing. One table in particular caused a lot of confusion, which required caregivers to read the questions on page four and respond in the table on page five. After the first focus group there was such a clear indication of a problem with this table that it was amended to improve its readability and comprehension for subsequent focus groups.

4.2.3 Language

Overall, the language of the guide was understandable and well received. Participants indicated that the language was appropriate for both men and women, inclusive of both masculine and feminine perspectives, and unbiased. Some participants described the overall language as “polite and cautious” and advised that the language could be more direct. For
example, on the cover of the FCGDG it was suggested we use more direct language like *palliative care* as opposed to *life-limiting illness*. This same advice was expressed regarding the perceived exclusion of specific end-of-life language. It was believed that more explicit end-of-life terms and concerns should be included in the FCGDG; including matters such as medical directives, wills, Power of Attorney, palliation and hospice. It is worth recapping that the focus groups were conducted with bereaved caregivers and hence they had already faced the death of their family member, conceivably making direct language more fitting. Current caregivers, however, may not relate so readily with direct language as the probable death of their family member may not be as immanent or accepted, making direct language potentially upsetting or offensive.

Language revisions were made to two additional sections of the guide as they were wordy or unclear. For example, participants found the question on the top of page six too wordy, which contributed to a lack of clarity. Elsewhere, particular words were pointed out as being either well liked or unfitting. One example is in the section where we asked participants to share two advantages and disadvantages regarding their care options if they could no longer care at home. The language of advantages and disadvantages did not fit for several participants, as was the request to list two specific advantages and disadvantages per option. Participants did not understand why they were asked to list two for each option, stating that it was unhelpful. Another participant further stated that the language made it hard for her to answer the question, because she did not think in those terms. The first group of participants suggested a simple amendment to this section so that it requested that caregivers note their reasons for liking or disliking various caregiving options, which proved to be an acceptable solution according to subsequent groups. Another example is where participants
were asked to consider how they are managing with *doing enjoyable things*. Some participants did not like this phrase because they experienced it as indicating a lack of understanding of the challenges of their caregiving situation, which in turn left negative impressions about the usefulness of the guide.

The guide addressed the perspectives of both the caregiver and the care recipient. Participants noted that in some sections it was clear whose perspective was being sought, for example, when the pronoun *you* was used. In other sections, this was not so clear and they recommended that we revise those sections for added clarity.

**4.2.4 Content**

Participants consistently told us that the content of the guide was useful. However, they also expressed the need for more explicit information on end-of-life choices and decisions, as well as more information and details regarding available resources and support services.

As previously mentioned, participants expressed a desire for more explicit language surrounding end-of-life issues. Participants indicated that this topic encompassed issues like medical directives, Do-Not-Resuscitate (DNR) preferences, wills, Power of Attorneys, funeral arrangements and arranging other necessary legal affairs. Participants stated that specific language was necessary because some people are not aware of these important issues or thought about them. Explicit language regarding conversations about care patients want at end-of-life was considered essential. Participants suggested that adding words like *hospice* and *palliative care* to the guide would be helpful in initiating conversations regarding end-of-life issues. It was further suggested that this kind of information helps family caregivers to prepare ahead of time, particularly if they lived in a rural area. This preparation was thought
to help family caregivers “avoid running by the seat of [their] pants.” Explicit content on end-of-life was, therefore, important to participants.

Participants also requested more specific content regarding resources and support services including a list of supports that were available and affordable in their area. Some participants were aware that supportive resources were available, however stated that they were difficult to access. One participant elaborated on how she felt that a certain level of lip service existed regarding services that were identified as available, which differed from what was actually accessible and affordable. Similarly, participants felt that the resources listed in the guide were helpful, but requested more information, such as “Where does the caregiver go from there to access resources and know the costs, etc.?”

Participants suggested that the FCGDG was “full of questions but requires more answers.” Adding some sidebars with extra information could be a support to caregivers, normalizing some of their experiences or offering ideas of what they might be able to expect as caregiving progresses.

4.2.5 Readability/ Comprehension

This aspect of the guide had fewer findings to report. Issues pertaining to this section of the guide were more or less secondary, or linked to the other aspects that were evaluated. For example, a few participants noted that in its original state, the guide was too burdensome to complete in the midst of caregiving. One participant noted that completing the guide would have given her a “headache;” the general readability overwhelmed her.

Several participants suggested that it would have been helpful to have a healthcare professional go through the guide with them. Participants generally comprehended the information in the guide and found it useful, however, believed that it would be more useful
if they reviewed the guide with a health care professional. The reasons were two-fold: some participants required help navigating the guide itself, while others desired someone to help link their responses to appropriate supports. Upon deeper consideration, the research team determined that the difficulties that participants had with the readability of the guide were not due to a lack of understanding of language or medical terms relating to the text itself, but rather due to layout or sequencing issues. Few suggestions or comments were made specifically regarding the comprehension of questions or statements in phase one; participants comprehended the language and the content of the guide. Comprehension or readability issues consequently appeared only as secondary to layout/sequencing issues, which will be discussed below.

4.2.6 Sequencing/Layout/Design

Findings from phase one of the study indicated that major sequencing and flow amendments were required, and thus were implemented before phase two of the research. Participants made comments relating to the layout of the guide, including statements such as “[the guide] reads as a study, where info is being collected, not as a helpful tool for caregivers.” Others said that the “format doesn’t fit [the] sensitive emotions of the process” and that it “needs a softer font” and “needs to look more appealing.” Participants noted the guide’s “raw format” and suggested that adding photos, quotes, or putting little facts or preambles that can act as dialogue, would help to personalize the guide. They specifically thought that pictures of people would help to personalize the guide, in addition to making it “lighter” and “softer.”
Participant responses indicated that the guide needed more writing space. Format changes to tables and charts were also strongly recommended. On a positive note, participants expressed that they appreciated that the guide did not contain small print.

Upon deliberation, the research team made sequencing and layout changes to the guide based on the difficulty that participants experienced. Committee members determined that the sequencing of the guide was not an accurate depiction of the flow of the caregiving decision-making process, and therefore changed the order and language of the over-arching four steps of the guide. The corresponding sections were re-ordered within the guide.

Despite participants’ strong recommendations to be more explicit with end-of-life content and language in the guide, the research team determined that such changes were not yet warranted. As previously expressed, this population consisted of bereaved caregivers, who may relate more readily to explicit end-of-life language, having already faced the loss of their family member. Current family caregivers may not relate to such language so readily or may even be offended by it, which would limit the guide’s relevance. Expanding on the palliative language and content of the guide raises considerable complexities that did not necessarily fit the guide’s original purpose. The FCGDG’s purpose is to provide decision support for family caregivers while caring for their family member at home, not to navigate the patient’s palliation. Consequently, the research committee determined not to include such recommendations at this stage, but to review the findings following the second phase of the research, which included current caregivers.

Based upon the feedback obtained in phase one, the guide was re-designed, including changes to the esthetics, format, tables, sequencing, and language. This revised guide was then submitted for ethical approval prior to phase two of the research.
4.3 Phase Two

4.3.1 Description of the sample

Cognitive interviews were conducted with eight current family caregivers. The sample consisted of five (63%) women and three (37%) men. The mean age of the participants was 56; one person did not record their age. Three participants lived in the same home as their family member while caring for them and five lived in a separate residence. Of the eight participants, three were retired and five were employed. Two of the employed participants reported brief or extended leaves from employment to accommodate caregiving demands. The caregiver relationships consisted of being spouses, siblings, and parents to the ill family member. The participants’ experience and current circumstances in caregiving allowed them to speak to the guide’s relevance, usefulness and comprehensibility for decision making. The findings are organized into five categories: images, language, content, readability/comprehension, and sequencing/layout/design.

4.3.2 Images

As discussed previously, on the recommendation of participants from the focus groups, the re-designed FCGDG included images with the intent of creating a more inviting resource. Participants reported they identified with the images and that they created a warm, caring, and personal feeling to the guide. In particular, the images on the cover invited caregivers to pick up and open the guide. Images of family members embracing or holding hands were viewed as “caring” and “symbolic of life,” reflecting a familiar experience, often emulating reflections of participants’ personal situations. Participants further noted that some
of the images helped them to “envision potential changes” which they viewed as helpful in preparing for future caregiving.

There were only two images viewed as unhelpful. The first was a blank picture frame image, a space created to insert a personal family photo. The intent was for the family to personalize the guide. However, this was met with much discomfort because several participants said that their family member’s appearance had changed drastically since their illness, often due to extreme weight loss. Consequently taking a photo, or inserting a past or present photo of their family member, evoked a negative response. The second image depicted a discouraged or depressed man, to which a participant responded: “I don’t need to see that.” The image was seen as unhelpful to the caregiver’s current situation. Both of these images were subsequently removed from the guide.

The majority of participants thought that the images expressed diversity of age, noting, “Caregiving can happen at any age.” One participant, however, found that there were no images to reflect her situation, that of caring for a young person who was ill. The images were not altered based on a single response.

In relation to diversity, research team members’ deliberations revealed a lack in ethnic diversity represented by the images. Though some ethnic diversity was reflected throughout the guide, a need for more was debated. Research team members agreed on the importance of adding more images portraying various ethnic backgrounds, particularly on the cover, since the cover is caregivers’ initial contact with the guide. Participants related personally to images that reflected their situation, which supports the need for an increase in ethnic diversity to be presented in the FCGDG.
The findings showed that the images overall contributed to a sense of personalization and relevance regarding the FCGDG, and addressed concerns expressed in phase one of the research. The changes made to the guide based on the findings from phase one, transformed the onerous “tax form” look into a warm and inviting support tool, which several participants stated they “would have picked… up for sure” had it crossed their paths.

4.3.3 Language

For the decision guide to be truly useful, it is essential for it to be understood. Many participants stated that it was hard to focus on ordinarily easy tasks while caregiving, due to being exhausted or emotionally overwhelmed. FCGs described becoming easily confused or overwhelmed with paperwork, which demonstrates the need for clear, easy to understand language in the guide. As the cognitive interviewing method indicates, participants expressed their initial thoughts about the language in the guide using the think out loud technique. Participants identified language throughout the guide that was particularly fitting for them and that which was not. Participants identified some language as appropriate when it described the essential balance in the caregiver-family member relationship. Participants expressed enthusiasm regarding language that succinctly expressed their sentiment or position. Some participants were expressive making statements like “excellent choice of words, because it’s exactly that, [it’s how I feel]” or “I like the language ‘how confident are you with…’ because it really makes you think about your caregiving.” Contrarily, when language was not a fit for the participant, they seemed perturbed and the corresponding question appeared to lose relevance. Furthermore, when language was not a fit, the participant expressed feeling like the writer of the guide did not understand what they were going through. For example, in light of the caregiver maintaining their own well-being, a
question asked how they were managing with *exercising and keeping active*. The language of exercising was emotionally provocative for many participants; one person compared it to “asking someone on an airplane to open a window.” This ordinary task simply did not make sense, or was thought not to be possible in the circumstances. Consequently, we removed the word *exercising* from the guide and retained *keeping active*. Similarly, several participants found the phrase *doing enjoyable things* did not fit; hence the phrase *involved in meaningful activities* replaced it.

Participants found that the guide was generally “easy to read and definitely understandable.” Participants pointed out that “sentences were short and simple for the most part” and that overall the guide was clear. Participants thought the guide was written in layman’s terms and viewed the language as appropriate. For example, a FCG stated: “it doesn’t read over someone’s head [and] that the average person should understand it easily.”

After deliberations, research team members changed the use of second-person pronouns to first-person throughout the FCGDG. This change reflected the belief that language expressed in the first-person creates a stronger action response in participants. This change further alleviated the few areas of confusion regarding the subject of the question. The amendment of first-person pronouns clearly indicated to whom the question was addressed, which clarified any outstanding confusion surrounding such language issues.

Further deliberations determined that the use of *loved one* throughout the guide, to describe the ill family member, was unsuitable. A current study, conducted by members of this research team, revealed a strong concern about the use of this term because it did not fit for all caregivers. Consequently, the research team determined to use the more neutral language of *family member* instead.
Participants expressed ambiguity towards the language of *life-limiting illness* on the cover of the FCGDG, but could not think of more suitable suggestions. Participants further noted that the use of language such as *palliative* or *terminal* was too aggressive, which contrasted the focus groups’ suggestion for including more direct language. Current FCGs described this language as sufficient because it described their family member’s situation, thus the language of *life-limiting illness* was not changed.

**4.3.4 Content**

Comments about the content of the FCGDG were related directly to the perceived usefulness of the guide. Participants offered the most feedback in this segment of the guide. Participants indicated that generally the guide was a useful and helpful tool. Participants recognized that while caregiving for a family member with advanced cancer, “needs change and transitions are unpredictable and that reviewing the guide at different stages is helpful.” The guide was, therefore, viewed as something that could help “stimulate that thinking, to address the changing needs.” All participants said that the guide “makes you think” or it caused reflection, which helped in the planning of future care, as the needs for care change over time. Many participants described how they “just learnt as they went,” and adapted to changes or needs as they arose. Participants claimed that the guide could help with planning; anticipating potential needs before crises arose. Some described being prepared for these changes, which was often due to “excellent health care” and open communication with their family members about their disease process and their care.

The guide appeared less useful to those who experienced “excellent health care.” These individuals explained that they received help from a physician, nurse, or palliative care team that offered valuable insight into the disease process and/or resources to help assess,
plan, and implement required care. This information paired with open communication with their family members appeared to lead to the most effective decision making. Participants who did not have similar “supportive” experiences with the health care system regarding end-of-life care (or received it later on in the process) stated that they could have greatly benefited from the use of the FCGDG. Those who recognized they reacted to instead of planned for changes in care needs, described feeling overwhelmed in their caregiving.

Participants perceived the preferable way to care for their family member as the ability to plan for options instead of reacting to circumstances. One participant described that dealing with things as they come, or learning as you go, can be “compromising to their [family member’s] health and your own.” Another participant pointed to the importance of planning to make the journey more smooth and successful. Participants strongly endorsed the FCGDG’s usefulness in accomplishing this goal: helping FCG to plan for future care. Participants stated that it helped make them aware of things that they previously were perhaps not aware of, such as definitions of care options like respite or hospice, as well as resources such as pet services, medication delivery, or medical equipment and supplies.

Participants described another fundamental aspect of decision making: conversations with their family members about their wishes for care and the feasibility of those wishes. Family caregivers described situations where they were not managing well with care at home; they recognized that changes were necessary, but conversations regarding such changes were seen as difficult. Participants pointed to the guide’s potential usefulness in initiating and navigating difficult conversations between family caregivers and ill family members. These conversations inevitably influenced caregivers’ decisions. One participant described the FCGDG as being “a bit of a map to have that kind of conversation.” The guide
was also said to “open doors” or “open possibilities for discussions.” One participant put it this way:

The steps [in the FCGDG] help you think through the stages and helps you to process, which you often don’t take time to do when caregiving. All of a sudden things are on you and you have to make decisions…[the guide makes] you stop to think, and it is very clear.

On another note, participants indicated that content related to exhaustion as a potential reason that caregivers are no longer able to keep caring at home was missing from the guide. The theme of caregiver exhaustion was consistent throughout the cognitive interviews and is congruent with the literature, which validated its inclusion in the guide.

Overall, the participants found the content of the guide useful and helpful; aiding them to reflect on their current situation, to plan for future care needs and to initiate difficult conversations with their family member, which they believed would assist them in their overall decision making. However, most participants suggested the guide lacked two important topics, which required more attention and detail to make the guide even more useful. These two main requests from participants (which were congruent with the data in phase one) were to include more information on how to access support services, their availability, cost and limitations; as well as addressing end-of-life issues more explicitly. To clarify, participants appeared to desire more explicit information on the issues that might arise near end-of-life, however, did not feel the need for language to be more explicit, such as *terminal illness*.

The accessibility of resources was of paramount concern for many caregivers. A few participants thought that the list of services on page ten of the guide sufficiently triggered
caregivers to consider services and supports available in their area. However, several others felt strongly that the guide should provide more concrete information; participants expressed the need for a list of services and their correlating phone numbers and websites. Several participants noted that more senior caregivers might struggle with websites, particularly if they were currently overwhelmed with caregiving, and that phone numbers were preferable where possible. Participants indicated that the guide had the capacity to make one aware of their need for more caregiving assistance, but that the guide did not help provide the answers to: “Where can I now access those supports? Can I afford those supports? Is my family member eligible for those supports?” Caregivers noted that often supports were wonderful once accessed, but that the process of finding them or accessing them could be difficult. Participants suggested the inclusion of an appendix at the back of the guide that listed a few general phone numbers where caregivers could access supports, such as hospice, palliative care team, home care, and Red Cross for equipment rentals. Research team members agreed upon the inclusion of a resource list that incorporated national level supports so as not to limit the FCGDG’s usefulness to one particular region. Furthermore, the purpose of the guide was not to encompass caregiving duties in their entirety, but rather to provide a useful tool in assisting family caregivers with decision making regarding caring in the home and beyond. Deliberations concluded that a general resource list be included on the back of the guide, however, more specific details on local resources, their costs and limitations could be discussed in more detail with one’s family physician or other health care provider.

Secondly, participants expressed a need to address end-of-life issues more explicitly in the guide. Participants talked of the significance of planning for all the end-of-life details in advance, yet sometimes people are not even aware of what these things are. For example,
one participant stated that she was told by a palliative care nurse to “get their affairs in order,” but she questioned, “What does that mean?” Participants unanimously expressed the importance of giving more information on end-of-life concerns such as medical directives, Do Not Resuscitate status, a legal will, a Power of Attorney, joint or accessible banking, funeral arrangements and any outstanding legal or financial affairs. Some participants acknowledged that the FCGDG need not include everything, but that naming and articulating some of these end-of-life issues was hugely beneficial to caregivers, because they might not otherwise recognize or address these important matters; because “when the loved one is gone, it’s too late.” Sensitivity with end-of-life language in the FCGDG presented itself as a complex issue (as will be discussed in Chapter 5). The research team learned that in order to keep the guide as an effective intervention, the language should remain relatively neutral to minimize offense to FCGs in varying stages of the palliative trajectory. While gentle introductions were offered to expose FCGs to potentially new options of care, such as hospice care, the guide offered space for individual reflection and for those at various stages of the trajectory further inviting FCGs to review the guide as needs changed.

4.3.5 Readability/Comprehension

The title of the guide (A family caregiver guide) appeared to be interpreted in ways that created unintended expectations for the resource. As depicted above, participants expected tangible and practical supports for their caregiving in the FCGDG. This was particularly evident as participants requested more answers to questions raised in the guide. One participant noted that the guide was good and helpful, but that “it would be a hell of a lot more helpful if it answered ‘Where do I go from here?’ or ‘Where do I get that info?’ Because there are a lot of questions, but not a lot of answers.” The FCGDG was, however,
not designed to be prescriptive in its content, but rather descriptive of possible caregiving options, to prompt reflection and insight that could be applied to each caregiving situation. Research team discussions revealed that this expectation for prescriptive answers was perhaps due to use of the language on the title page; “A family caregiver guide.” The title more accurately should have read “A family caregiver decision guide.” The committee recognized that the omission of the word decision in the title was an error that conveyed a different intention regarding the purpose of the FCGDG. Therefore, the word decision was added to the title page. We hope that this amendment clarifies the guide’s purpose in serving as a guide for the complex decisions that families must make, rather than a comprehensive guide to address all of families’ tangible caregiving needs and limitations.

Participants further noted other areas where comprehension of the guide’s intent was not clear in a few areas, and where the addition of a clarifying or instructional statement or header could alleviate the confusion and increase the readability and comprehension of the questions at hand. For example, on page four, one participant was confused as to whose pain control we were referring. The heading of the section read “How are you managing with…” followed by several items including “pain control.” A participant suggested that adding “My family member’s pain control,” clarified the confusion.

One participant became quite flustered upon reading the heading on page five. It read: “Caregiving can be challenging and it’s not always easy to keep healthy.” The following question read: “Overall, how well are you managing caregiving now?” The participant felt that these two statements did not correlate and hence was confused by their joint presentation. He noted that he was currently managing quite well with his caregiving, but that
did not mean he was necessarily keeping healthy. The committee made changes to both language and layout to increase readability and comprehension of this page.

Another area that caused some confusion was on page 11. The question read, “What are your best options if the needs for care change, or if you can no longer care at home?” The options then proceeded to list home as the first option. A participant questioned: “How can home be an option, if you can no longer care at home?” Upon deliberation, the research team members agreed that the intent of the question was to explore options beyond the home if caregiving was no longer possible at home. The question was therefore changed to “What are my best options if the needs for care change and I can no longer care at home?” Additionally, we removed the first option of “home” from the options on pages 11 and 12.

Furthermore, participants in phase two of the research did not request that a health care professional go through the guide with them. This differed from phase one of the research where participants suggested that assistance going through the guide would have been helpful. Participants in phase two thought that this would be a valuable guide to keep at home for their continued use. It was apparent through their interviews that they viewed this guide as a tool that they could and would use on their own. The guide triggered reflections or questions that they in turn could ask their physician or health care provider, but that assistance was not required to work through the guide initially. This may have indicated that the comprehension and readability of the guide was significantly improved, and could hence be used independently by the family caregiver. However the demographics of each phase of the research were quite different, with the mean age of FCGs being significantly younger in the second phase. Further, having a health care professional complete the guide alongside family caregivers may help link their responses to appropriate supports, as suggested in phase
one of the research. This would potentially address the feedback regarding the need to elaborate upon and provide more information on how to access support services, their availability, cost and limitations.

4.3.6 Sequencing/Layout

Participants did not point out any issues or problems with the sequencing. Rather, research team members identified sequencing concerns through discussions of the data as a whole. For example on page three, we asked caregivers how they were managing with various activities related to caregiving, varying from home maintenance to personal care of their family member, and their family member’s pain control and symptoms. After reading the list of activities on page three, one participant stated that we had omitted transportation to and from medical appointments, which minimized its importance. However, we had in fact listed transportation on the top of page four, where the list continued. Research team members suggested that this list be kept on the same page and not be separated onto two separate pages in order to maintain the continuity of the thought. Similarly, the initial question on page five related to the content on pages three and four, and as it was not a fit with the heading on the page, we repositioned this question to the bottom of page four, where the content was of the same focus. Such sequencing changes improved the flow of the guide by keeping similar content to the same space.

Further, in some places it was difficult to match the statement with the corresponding tick box and so the formatting was changed.

4.4 Summary

In summary, in this chapter the findings from the assessment of the FCGDG were presented. Overall, participants considered the guide a useful and helpful tool in caring for a
family member with advanced cancer at home. Phase one of the research revealed that despite the helpful information in the guide, the onerous format distracted and confused participants from the content of the guide. The subsequent changes in the format and layout of the guide, in addition to the inclusion of inviting images, were made to improve the guide’s usefulness for caregivers, and invite them to reflect and personally relate to the guide and its content. The feedback from phase two of the research revealed a comprehensive and understandable guide that caregivers perceived facilitated their reflections and decision-making processes. Following amendments to the guide in phase one, participants found the FCGDG to be “clear, self-explanatory and complete,” stating it was “very useful; a great resource.” Participants further indicated that the guide prompted reflection (which was seen positively) and facilitated discussions regarding caregiving options. Despite participant feedback on the potential usefulness of the FCGDG, data from both phases one and two of the research revealed two main deficiencies. Firstly, suggestions were made to elaborate upon and provide more information on support services including their accessibility, availability, cost and limitations; and secondly, participants requested that end-of-life issues be addressed more explicitly.
Chapter 5. DISCUSSION

5.1 Overview

There is a growing emphasis on the provision of home-based palliative care in Canada, which is consistent internationally (Chai, Guerriere, Sagorski & Coyte, 2014; Payne & Grande, 2013). It is well documented that FCGs carry much of the responsibility associated with caregiving in the home, specifically at end-of-life (Chai et al., 2014; Hudson & Payne, 2011; Robinson et al., 2012; Stajduhar, 2013). However, FCGs are often ill-equipped for the enormity of the physical, emotional, and relational challenges associated with palliative caregiving and caregiving at end-of-life (Robinson et al., 2012; Statistics Canada, 2012; Topf et al., 2013). Despite such demands, FCGs remain committed to providing excellent care to their family members who have advanced illness, but often lack the support needed to accomplish this goal (Robinson et al., 2012; Topf et al., 2013). The aim of the FCGDG was to help FCGs navigate their way through the decisions and processes of caring for their palliative family member at home and furthermore to assist FCGs in understanding the intricacies around the care they would be giving. The research team evaluated the guide’s usefulness and suitability in achieving these goals.

Phase one of the research revealed areas of the FCGDG that required amendment to improve the guide’s readability and understandability, which focused on changes to the format and layout of the guide, in addition to the inclusion of inviting images. Following these amendments, in phase two a revised guide was presented to FCGs. Data indicated that FCGs found the revised guide comprehensive, understandable and useful, and that it invited them to reflect and personally relate to the guide and its content. Further, participants said that they thought the guide would help them initiate conversations with their family members.
and care providers regarding future care needs, preferences and planning, which in turn would assist their decision-making processes.

Despite FCGs’ feedback on the guide’s potential to assist their decision-making processes, the findings showed that the educative reflection was not enough on its own. FCGs were still in need of more tangible resource supports; the guide helped FCGs become more aware of what it was that they needed, but they were too overwhelmed and exhausted to then attain those needed resources or supports on their own. Suggestions were made to elaborate upon and provide more information on the accessibility, availability, cost and limitations of support services, as well as to address end-of-life issues more explicitly. Despite the request to be more explicit about end-of-life issues, findings revealed complexities surrounding timeliness of language at end-of-life. Furthermore, the research team noted that when the focus of the guide was on the FCGs, specifically their self-care, instead of the ill family member, it disrupted their connection to the guide, which compromised the effectiveness of the intervention.

In this chapter, the key findings from the evaluation of the FCGDG are discussed in relation to the existing literature and our current understanding of family caregiving in palliative care and end-of-life. This discussion is organized around the following headings: extending decision support interventions to FCGs, the effectiveness of the FCGDG in engaging FCGs, recognizing timeliness of language, addressing FCGs’ self-care, and linking FCGs to tangible resources. This will be followed by a discussion of the recommendations for practice, policy and research, and the significance of the study.

5.2 Extending Decision Support Interventions to FCGs

Decision support interventions have arisen in response to a move toward patient
centered care and the importance of shared decision making within that orientation (Carman et al., 2013; Durand et al., 2013). “Patient- and family-centered care” is a term that suggests an image of what health care should be: a partnership between practitioners, patients and their families to ensure that decisions respect the patients’ needs and preferences (Carman et al., 2013). While family is mentioned in patient-centered care, its focus really is on the individual who is sick. A family-centered perspective, however, is important in palliative care (Blum & Sherman, 2010), because the patient’s ability to stay at home often rests on family caregiving (Bastawrous, 2012; Funk, Stajduhar, Toye, Aoun, Grande & Todd, 2010; Stajduhar, 2013). FCGs caring for individuals with various life-limiting illnesses have an integral role throughout the illness trajectory and play a crucial part in the decision-making process (Hogden, Greefield, Nugus & Kiernan, 2013; Sanford, Townsend-Rocchicciolli, Horigan & Hall, 2011). Edwards, Olson, Koop and Northcott (2012) describe this “delicate and precarious” decision-making process as “dancing on the stairs” (p.178), which incorporates many intricacies such as: moving in tandem, managing the steps, and taking the lead. A grounded theory study which focused on FCGs of people with heart failure described the FCG decision-making process as including “actualizing; seeking input, information, or support; reflecting; choosing; evaluating; and validating the decision” (Sanford et al., 2011, p. 55). Sanford et al. (2011) further noted that FCGs are required to make more decisions as the patient progresses further along the palliative trajectory. Despite little being known about how FCGs make decisions for, or with, their family members, our study extends the idea of decision support to FCGs. As previously identified, there is an international “call” to develop interventions to support FCGs (Chai et al., 2014; Payne & Grande, 2013). However, the specific need for decisional support has not yet been identified in the literature. This study is
uniquely progressive in multiple ways: extending decisional support to specifically focus on FCGs and presenting an intervention to address FCG decisional needs.

This intervention, the FCGDG, was built around a step-wise decisional process, which was adapted from an internationally recognized, evidence informed approach and standards for the development of patient decision aids (Elwyn & O’Connor, 2009; Joseph-Williams et al., 2013). The International Patient Decision Aids Standards (IPDAS) Collaboration outlined internationally recognized standards for a good decision aid (Elwyn & O’Connor, 2009). IPDAS addressed three main areas for guide development and evaluation: information and values clarification, development process, and effectiveness (Elwyn & O’Connor, 2009). The FCGDG is similar to traditional decision aids in that it provides information that participants indicated has sufficient detail to support decision making, presents information in an understandable and unbiased way, offers methods for clarifying and expressing participant’s values, and includes guidance on deliberation and communication surrounding decisions (Elwyn & O’Connor, 2009). The FCGDG was developed through a systematic process (including a literature search and field testing with those facing the decisions), and uses up-to-date scientific information and plain language that participants found understandable and applicable (Elwyn & O’Connor, 2009). Lastly, the guide is similar to traditional decision aids in ensuring that decision making is informed and value-based, which assisted participants to understand their options and how they fit with what mattered most to them (Elwyn & O’Connor, 2009). Consequently, the field-testing of the FCGDG demonstrated the value of the guide to FCGs by demonstrating its acceptability, understandability, applicability and helpfulness, according to international standards (Elwyn & O’Connor, 2009).
5.3 The Effectiveness of the FCGDG in Engaging FCGs

Through the process of field testing the FCGDG valuable lessons were learned about what engages FCGs in decision-making processes and when these issues were attended to participants perceived the guide as a useful tool for decision making. As mentioned, little is known about how to effectively engage FCGs in a planned decision-making process (Stajduhar, 2013) and so this study makes an important contribution. Researchers have described family palliative caregiving experiences; however, gaps in understanding exist surrounding how to effectively support caregivers (Hudson & Payne, 2011; Stajduhar, 2013). The importance of assessing and addressing FCGs’ needs through relevant interventions is highlighted in the literature (Hudson & Payne, 2011; Stajduhar, 2013). The guide was developed as an intervention and addresses this gap.

This study further extended the development process of a support intervention by attending to the engagement of participants with the decision guide. In order to be useful for FCGs, the guide needed to be something they would spend time with. Developers of decision aids are not commonly concerned with esthetics, which was evident with the original version of the FCGDG. The original version had no images and participants thought it looked like a tax form, which they said would make it difficult to pick up and use. We learned that esthetics mattered to engagement in the decision-making process that is the foundation of the guide. The FCGDG is an intervention aimed to help FCGs think and plan ahead, which in turn offers insight into effective decisions regarding care. However, in order for the FCGDG to be effective, we learned that it needed to be visually appealing while demonstrating personal relevance, which goes beyond current standards for the development of decision aids.
It became apparent to the research team that when participants could see themselves and their caregiving experience reflected in the guide, they connected with the material and became engaged in the process of working through the guide. What helped or hindered this connection and subsequent engagement was the format/layout of the guide and, in particular, the images in the guide. Based on the findings of the current study, an effective way to engage FCGs, or conversely to alienate FCGs, in the educative and reflective process, is through the use of images. It was important for FCGs to see representations of themselves or their situation in the guide in order to relate to the benefits of the information in the guide. When FCGs were able to see their caregiving situation reflected through the images of the guide it generated a connection to the guide, which resulted in engagement in the educative and reflective benefits of the FCGDG, fulfilling its original intent of decisional support.

Visual methodologies are increasingly being used in research (Chapman, Hall, Colby & Sisler, 2013; Nalavany & Carawan, 2010). Images have been shown to help prompt and facilitate difficult conversations, for instance conversations that address individuals in specific circumstances such as end-of-life decisions (Chapman et al., 2013). Though images were not used as a methodology in this thesis research, their effect on participants was similar. Findings from Chapman et al.’s (2013) study described how “images effectively engage[d] participants in discussion, elicit[ed] openness and reflection, and increase[d] empathy” (p.456).

This section addresses one aspect of what the participants have helped us understand about the creation of an effective resource. It is that the resource needs to be something individuals can connect to in a way that is meaningful; FCGs need to be able to see a reflection of themselves in the guide to engage and images helped to facilitate this
engagement. Once FCGs were engaged, they were then willing to spend the time to work through the process. Another aspect that participants have helped us understand is the timeliness around language.

5.4 Timeliness Around Language

Cancer patients and their caregivers often experience barriers in properly processing information based on the language used (Martinez-Donate et al., 2013). The importance of receiving information at the appropriate time may be just as relevant as the content of the information being given.

We know that caregiving changes over time, sometimes very quickly, and that multiple decisions are made in response to changes (Edwards et al., 2013); the intent of the guide was that it be used repeatedly in response to such changes. This differs significantly from traditional decision aids, which support a specific singular decision (person comes to a decision they can live with when there is no clear right or wrong answer; Stacey et al., 2014). Knowledge is lacking about what FCGs experience throughout the changes or transitions that are common to the context of palliative caregiving (Blum & Sherman, 2010); however, FCGs gave us a glimpse in their response to the language used in the FCGDG.

The participating FCGs had different responses to the language in the guide depending on where their family member was on the illness trajectory. Patients and their FCGs are not always accepting of the palliative process or may be in denial regarding the need for palliative care; however, the World Health Organization (WHO) explicitly recommended early integration of palliative care in the disease trajectory (Gaertner et al., 2010). The guide was intended to be used and useful for FCGs who are early in the palliative caregiving journey. However, referrals to palliative care often happen late in the trajectory of
illness for patients with cancer (Fadul et al., 2009). Terminology surrounding palliative care in the cancer trajectory has been raised as a possible barrier to early referral (Fadul et al., 2009; Gaertner et al., 2010). We saw this in our study as participants who were bereaved desired explicit end-of-life language; whereas, other participants who were still in the midst of caregiving (earlier stages of the trajectory) did not want language that was too explicit concerning end-of-life. Emerging literature shows that the use of palliative language evoked more negative emotions among patients, their families and health care staff, reducing hope and carrying synonymous meaning with end-of-life care (Fadul et al., 2009; Miyashita et al., 2008; Morstad Boldt, Yusuf & Himelstein, 2006). Current FCGs in our study generally related well to the less explicit end-of-life language used in the guide. However, some current FCGs, usually further along in the palliative trajectory, suggested that more explicit end-of-life language be used in the guide. This highlights the tensions associated with choosing language that is acceptable to caregivers throughout the illness trajectory and into bereavement.

A recent longitudinal study has highlighted how not only palliative patients are affected by the palliative trajectory, but how FCGs are affected as well (Stamataki et al., 2014), which was consistent with our study. The caregiving experience is a dynamic process that changes over time (Blum & Sherman, 2010; Edwards et al., 2012; Stamataki et al., 2014). Based on interviews with 53 FCGs over a period of 12 months following their family member’s cancer diagnosis, Stamataki et al. (2014) describe how primary and secondary stressors influence the way FCGs perceive caregiving demands (Stamataki et al., 2014). The stress process can occur anywhere within the cancer trajectory, but is experienced uniquely throughout different phases (Stamataki et al., 2014). This study expanded on the idea that the
caregiving process changes over time and individuals may experience stressors differently at varying points within the cancer trajectory. Therefore, FCGs may be more sensitive to palliative or end-of-life language at various points in the cancer trajectory, which indicates that timeliness of language is a legitimate concern amongst FCGs caring for family members along the palliative trajectory.

We concluded that in order that the guide be acceptable and useful to a broad range of FCGs, the end-of-life language should remain less explicit to minimize offense to FCGs, especially those earlier in the palliative trajectory. While gentle introductions were offered to expose FCGs to potentially new options of care, such as hospice care, the guide offered space for individual reflection and was acceptable to FCGs at various stages of the trajectory, which further invited FCGs to review the guide as needs changed. Sensitivity surrounding language was not limited to the illness trajectory, but was also required regarding FCG self-care.

5.5 FCG Self-Care

FCG self-care refers to the caregiver’s ability to look after their own wellbeing. However, current evidence indicates that while FCGs are caring for their family member, they become solely focused on the person for whom they are caring, often at the neglect of many of their own needs or wellbeing (Robinson et al., 2012; Stajduhar, 2013; Topf et al., 2013). The importance of FCG self-care is clear; however, addressing FCGs’ responses to improving self-care is challenging.

We learned from this study that FCGs reacted to certain language around self-care. Language that reflected FCGs’ ability to exercise or do enjoyable things was met with resistance. FCGs were opposed to the notion of focusing on themselves, particularly in
relation to enjoyment, while their family member was suffering. Many FCGs found language that focused on self-care offensive and consequently felt that the reality of and demands on their caregiving experience were not well understood by the researchers. It was not that self-care was not an issue, but that it had to be reframed in a more sensitive manner. Focusing on themselves only appeared to be acceptable if it was framed in the context of caring for themselves to enable them to better care for their family member. The intent of focusing on self-care was positive, but emphasizing it was problematic. This finding was supported by previous work (Robinson et al., 2012; Topf et al., 2013). Robinson et al. (2012) described that a major theme in becoming a family palliative caregiver included becoming ‘other’ focused. This involved realigning priorities that focused on their ill family member’s needs and further influenced FCGs’ ability to self-care (Robinson et al., 2012). This selfless focus often arose from a profound desire to be an excellent palliative caregiver (Robinson et al., 2012). To shift the focus away from their family member’s care and onto the FCG disrupted their connection to the guide and compromised the effectiveness of the intervention.

We learned through the study that a focus on FCG self-care could be problematic, as an inward focus on self was often incongruent with FCGs’ priorities. FCGs deeply desired to be excellent caregivers, and better understood the importance of self-care when it reflected their capacity and ability to better care for their family member (Robinson et al., 2012). In order to maximize the effectiveness of the guide as an intervention, we must better respect FCGs’ need to be excellent caregivers and orient the focus on FCG self-care to this outcome. As a health care system, we must stop telling FCGs to better care for themselves, and instead start offering them the support that allows them to do so.
5.6 Linking to Tangible Resources

The FCGDG was designed to raise questions that invited participants to reflect on their individual caregiving situation. However, answers to these questions were not presented in the guide. Providing answers in the guide was not feasible because the goal was to develop a guide that could be used wherever FCGs resided and local resources vary greatly. However, participants were concerned about unanswered questions and how or where they would get support especially since they experienced challenges accessing resources, had time and energy constraints, and were often tired or exhausted. These FCG experiences are not uncommon and have been reported elsewhere (Bialon & Coke, 2012; Collins & Swartz, 2011; Hearson et al., 2011; Hudson & Payne, 2011; Robinson et al., 2012; Topf et al., 2013).

Throughout the study, participants frequently stated “this is great, but now what?” FCGs thought that the information in the guide was helpful in guiding them through the many decisions that needed to be made, but then wanted to know how those decisions could be supported tangibly. Participants thought that a better understanding of the process was not enough; they wanted access to more tangible supports, to help manage the practical demands of caregiving and to achieve their desired care goals. FCGs wanted a connection to local resources and supports, which could be achieved, for example, through the involvement of a health care provider. We learned that participants were comfortable working through the guide on their own (i.e., didn’t need a health care provider with them) but that they did need a connection after working through the guide.

This raises the concern that the guide may create distress by raising questions without answers, for example, if FCGs became very aware of what they needed while working through the guide, and then were left unsupported by the health care system in meeting those
needs this may lead to distress. Participants expressed that sometimes it felt like the health system was paying them lip service in presenting available supports, when in reality they did not qualify for services or services fell short. Others stated that they knew supports existed, but they did not know where or how to access them. FCGs have been reported to often feel exhausted and overwhelmed with information (Martinez-Donate et al., 2013), which makes it difficult to navigate the system on their own. Consequently the care coordination role, known as a patient navigator, has been proposed as relevant for this population (Martinez-Donate et al., 2013; Wye et al., 2014). Patient navigation offers support to cancer patients with the goal of improving access and coordination of timely care (Freund et al., 2014). The main functions of navigators are to identify and remove barriers to care (Freund et al., 2014).

In our study, FCGs described barriers to accessing needed resources to continue to successfully provide care at home. This finding is supported by others who have reported that FCGs need navigational help in relation to multidimensional needs, ranging from self-management, decision making, and psychosocial and financial support (Martinez-Donate et al., 2013; Van der Plas et al., 2013). Though care coordination or navigational support is relatively new to palliative care (Van der Plas, 2013), it is emerging as a successful intervention (Kreimer, 2014; Wye et al., 2013). Wye et al. (2014) describe the increased success of FCGs in providing care in the home until death when a skilled health care professional was involved in the coordination of their care. This navigational support was diverse in nature and included formal and informal knowledge that helped FCGs access community resources to support care at home (Wye et al., 2014). Hence, navigational support could be a worthy consideration in bridging the gap between identifying needed resources and accessing them.
The FCGDG has the capacity to help FCGs work through many decisional needs throughout their caregiving trajectory, through the facilitation of reflection, education and conversation. However, this process has the potential to raise questions without providing answers, which could be concerning to participants. We learned that the guide used in isolation did not provide FCGs with the maximum support needed, thus the FCGDG is an intervention that could be most effectively used when combined with navigational support.

5.7 Implications for Practice, Policy, and Research

Thorne (2008) described the significance of research in expanding knowledge in a specific field, identifying its contributions to the existing literature, and directing future inquiries. The findings from this study increase attention to FCGs and how to more effectively support them. This section highlights the implications of the study findings to practice, policy and future research.

5.7.1 Implications for practice

The findings from this study give direction for practice because they demonstrate that decisional support is both desired and useful. This guide was viewed as a useful tool in initiating reflection and conversations regarding planning for future care and decision making. However, an important implication for practice is that the guide is not a stand-alone intervention; FCGs desired information about practical supports available to them and required assistance accessing them. Therefore, this guide should be used in conjunction with the support of a knowledgeable health care provider, more specifically a health care navigator. Pairing the guide’s decisional support with tangible navigational support could maximize FCGs’ ability to provide appropriate palliative and end-of-life care.
This study highlights that a focus on FCG self-care is problematic. We put FCGs at greater risk of burden by urging a focus on self-care while caregiving and, at the same time, risk our relationship with them (Robinson et al., 2012). It is helpful to rather frame the need for self-care as an important factor to enable FCGs to provide the best care possible for their family members, for the longest time possible.

5.7.2 Implications for policy

As more end-of-life care is being provided in the home by FCGs, there is an expectation that palliative care can be supported in the home with adequate preparation and resources (British Columbia Ministry of Health, 2013). Despite growing efforts to support care at home for those with life-limiting illness (British Columbia Ministry of Health, 2013), findings from this study indicated that FCGs are still under supported and struggle to access the resources they need. Our desire is for policy to reflect the key position of FCGs in a way that directs attention and support.

Manitoba was the first Canadian province to pass a caregiver recognition act, which recognized caregivers as individuals with their own needs within and beyond the caring role (Funk, 2012). However, the literature describes how FCGs often were not recognized as having their own needs and often did not qualify for the supports they needed; supports were frequently based on the care recipient meeting rigid standards to qualify for supports, which often left FCGs feeling isolated and unsupported (Chai et al., 2014; Essue et al., 2010; Hudson & Payne, 2011). Awareness must be raised to recognize FCGs as individuals with their own support needs. Further, we must recognize the essential resource that FCGs are to our current health care system (Chai et al., 2014; Funk, 2012).
With the increasing age demographic in Canada, more and more individuals at end-of-life are being cared for in their homes which increases the need for FCGs (British Columbia Ministry of Health, 2013; Dykeman & Williams, 2014; Funk et al., 2010). At the same time, concerns exist regarding a future shortage of FCGs (Essue et al., 2010; Funk, 2012). It is imperative that policies support FCGs in their role. One way in which policy could better support FCGs is through increased resource allocation, which would facilitate longer, and more effective palliative care in the home. FCGs need increased tangible supports to effectively care for their dying family member at home, which includes help accessing existing supports such as palliative and hospice care (Essue et al., 2010); only 16%-30% of Canadians currently have access to hospice, palliative and end-of-life care services (Canadian Hospice Palliative Care Association, 2013). FCGs and their families could better access these needed supports if navigational support were extended to FCGs. The FCGDG could easily be put into practice as one component of support for FCGs, but it is not a ‘stand-alone’ intervention.

There is a movement toward home being the best place to die but supports and resources have not followed. We must ensure that current health care policies align with FCGs’ needs for accessible and tangible supports.

5.7.3 Implications for research

The FCGDG was designed for FCGs to revisit at various points along the palliative trajectory; however, this study only examined FCG perspectives at one fixed point. Longitudinal studies of the FCGDG would add insight into its effectiveness and usefulness throughout the caregiving trajectory. Longitudinal studies could also shed more light on how best to address the problematic language surrounding end-of-life.
It would be beneficial for future studies to incorporate a more diverse sample, both in age and ethnicity. It would be of particular interest to assess the responses of an older caregiver demographic because the Canadian population is aging and more elderly are caring for family members with life-limiting illnesses at home (Carstairs & MacDonald, 2011; Fowler & Hammer, 2013; Statistics Canada, 2012). Feedback from the elderly would help to evaluate the guide’s effectiveness with this population and their ability to use the guide independently, which may better inform its combined use with patient navigation. Future studies might also evaluate the FCGDG’s effectiveness when paired with a patient navigator to assess outcomes when the guide is used in this way.

5.7.4 Study significance

This thesis expands on current knowledge of FCGs, their need for greater support throughout their caregiving experience, and what comprises an effective intervention. FCGs describe the FCGDG as a helpful tool that could be a valuable asset to their decisional process. However, the findings must be considered within the context of the study. The interviews were conducted with both bereaved and current FCGs, but data were only collected once within their trajectory, which limits our understanding of how needs change along the continuum. In addition, although valuable reactions to the FCGDG were gathered, FCGs did not actually use the FCGDG to guide their decision making about care giving. It was beyond the scope of this study to describe the outcomes of using the guide. We also caution readers that the FCGDG has not been piloted with diverse populations or with the really elderly. The sample for this study was recruited from the same health authority, was relatively small, homogenous, and focused on FCGs caring for family members with
advanced cancer. The findings may not reflect the experiences of other FCGs caring for individuals with other life-limiting conditions.

5.8 Conclusion

This study adds to the growing body of knowledge on FCGs caring for someone with a life-limiting illness at home and their need to be adequately supported. I conclude that based on feedback on the FCGDG, the guide shows promise as an effective intervention. The findings from three focus groups of bereaved FCGs and eight individual cognitive interviews with current FCGs highlighted the need for personal engagement and reflection on the caregiving process along with the need for increased tangible supports. FCGs’ ability to engage with the guide was either enhanced or disrupted depending on their ability to relate personally to the guide. When FCGs personally engaged with the FCGDG, they found that it invited reflection on their current caregiving situation. FCGs also thought that the guide would help them initiate conversations with family members regarding future care needs, as they recognized that care needs changed over time. The dynamic reality of caregiving revealed complexities relating to the importance of timeliness around language; FCGs reacted differently to language specific to end-of-life based on where they were in the palliative trajectory. Less explicit language about end-of-life was consequently used to respect various stages of the palliative trajectory and maximize FCG engagement in the guide. Sensitivity was further required surrounding language targeting FCG self-care because we learned that a focus on FCG self-care also disrupted connection to the guide and compromised the effectiveness of the intervention. Despite feedback regarding the guide’s general usefulness, it was determined that the guide was not a stand-alone tool; it was recommended that the FCGDG be used in conjunction with navigational support. Although
the guide has the potential to increase FCGs’ awareness of their support needs, pairing the use of the guide with navigational support would help to ensure FCGs are able to access available resources. Support interventions like the FCGDG address the pressing need for developing new approaches to enable FCGs in providing the best care possible and supporting the quality of life of their family members experiencing life-limiting illnesses.
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APPENDICES

Appendix A: Information About a New Study

THE UNIVERSITY OF BRITISH COLUMBIA

Faculty of Health and Social Development
3333 University Way
Kelowna, B.C. Canada V1V 1V7

Information About a New Study
Caring at Home for Someone With an Advanced Life-Limiting Illness: Family Decision Guide

We have developed a decision guide for family members who are caring for someone at home who has an advanced life-limiting illness. The ultimate goal of this research is to help family members give the best possible care at home, for as long as possible and to also stay healthy themselves. We are interested in speaking with people who have experience providing home care for their family members with an advanced life-limiting illness. We would like to invite you to consider participating in a focus group with other caregivers to discuss and review the decision guide. You will have the opportunity to review the decision guide and then give your feedback to the team. The feedback will be used to improve the decision guide.

If you are interested in hearing more about this study, would you please contact Alexandra Rothenberg at alexandra.rothenberg@ubc.ca or by phone at 250 807-8174. Alternatively, you can sign and return the enclosed Consent to Contact Form in the stamped, addressed envelope we have provided and we will contact you.

Thank you very much for thinking about this.

Sincerely,

Carole A. Robinson, PhD, RN
Associate Professor
School of Nursing and
Principal Investigator
Appendix B: Consent to Contact Form

THE UNIVERSITY OF BRITISH COLUMBIA

Faculty of Health and Social Development
Fine Arts and Health
3333 University Way
Kelowna, B.C. Canada V1V 1V7

Consent to Contact Form
Caring at Home for Someone With an Advanced Life-Limiting Illness: Family Decision Guide

This is to inform you of a research study involving the UBC-Okanagan School of Nursing, funded through the Institute for Healthy Living and Chronic Disease Prevention at UBC-Okanagan. We are requesting your permission to contact you with more information regarding a study focused on the development of a decision aid for FCGs of someone with an advanced life-limiting illness.

The purpose of the research is to develop a decision aid for FCGs of someone with an advanced life-limiting illness. The ultimate goal of this research is to help FCGs with providing better care at home for as long as possible. We are interested in speaking with individuals who have experience with providing home care for their family members with an advanced life-limiting illness. The discussion will take place among a small group of caregivers. We would like these individuals to provide their feedback after completing the decision aid. The feedback will be used to improve the decision aid.

At this time, we are asking only for your permission to be contacted to hear more about the study. We ask that you please sign and return this form and we will respond accordingly. Alternatively, you can contact us directly by calling or emailing Alexandra Rothenberg (information below). If you indicate that you would like to be contacted, we will provide you with more details about the study and you can make a decision about whether you would like to participate. Your participation in this study is entirely voluntary. You may refuse to participate without any consequence to you or the supports and services you receive.

For more information about the study, please contact:
Alexandra Rothenberg, Research Coordinator
Tel: 250-807-8174
Email: alexandra.rothenberg@ubc.ca
Please tick one of the following:
  □ I would like to receive more information about the study.

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<th>Name (please print)</th>
<th>Signature</th>
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Please return this form to ____________________________ or, if you prefer to call us directly, phone Alexandra Rothenberg at 250-807-8174 (email alexandra.rothenberg@ubc.ca) and leave a message. We will get back to you as soon as possible.
Appendix C: Information About a New Study: Previous study participants

THE UNIVERSITY OF BRITISH COLUMBIA

Information About a New Study
Caring at Home for Someone With an Advanced Life-Limiting Illness: Family Decision Guide

Dear [participant]

We are contacting you because you participated in a research study conducted by Lorrianne Topf, and indicated on your consent that you agreed to be contacted in the future with information about participating in new research studies.

We have developed a decision guide for family members who are caring for someone at home who has an advanced life-limiting illness. The ultimate goal of this research is to help family members give the best possible care at home, for as long as possible and to also stay healthy themselves. We are interested in speaking with people who have experience providing home care for their family members with an advanced life-limiting illness. We would like to invite you to consider participating in a focus group with other caregivers to discuss and review the decision guide. You will have the opportunity to review the decision guide and then give your feedback to the team. The feedback will be used to improve the decision guide.

If you are interested in hearing more about this study, would you please contact Alexandra Rothenberg at alexandra.rothenberg@ubc.ca or by phone at 250 807-8174. Alternatively, you can sign and return the enclosed Consent to Contact Form in the stamped, addressed envelope we have provided and we will contact you.

Thank you very much for thinking about this.

Sincerely,

Carole A. Robinson, PhD, RN
Associate Professor
School of Nursing and
Principal Investigator
Appendix D: Informed Consent Form: Focus Groups
THE UNIVERSITY OF BRITISH COLUMBIA | OKANANGAN

Informed Consent Form: Focus Groups with Persons Who Have Experience Providing Care at Home for Their Family member With an Advanced Life-Limiting Illness

Caring at Home for Someone with an Advanced Life Limiting Illness: Family Decision Guide

**Principle Investigator:**
Carole Robinson, School of Nursing, University of British Columbia Okanagan, 250-807-9882

**Co-Investigators:**
Joan Bottorff, School of Nursing, University of British Columbia Okanagan
Barbara Pesut, School of Nursing, University of British Columbia Okanagan
Natalia Polchenko, Gerontology Department, Simon Fraser University
Janelle Zerr, Masters Nursing Student, University of British Columbia Okanagan

**Study Background**
The purpose of the research is to develop a decision aid for FCGs of someone with advanced life-limiting illness. The ultimate goal of this research is to help FCGs provide better care at home for as long as possible, while also maintaining their own health. We are interested in speaking in a focus group setting with individuals who have experience providing home care for their family members with advanced life-limiting illness. These individuals will contribute to the development of the aid by providing feedback and suggestions after completing the decision aid.

**Funding**
This research is funded through the Institute for Healthy Living and Chronic Disease Prevention at the University of British Columbia (UBC).

**Study Procedures**
You are being asked to voluntarily participate in this study because you have experience providing care at home for a family member with an advanced life-limiting illness. We are interested in your feedback about the decision aid, ‘Caring at Home for Someone with an Advanced Life Limiting Illness: Family Decision Guide’. Your participation will involve completing the decision aid and then discussing it in a small group with up to eight participants who have similar experience of providing care at home. We will ask broad questions about the decision guide: i.e. were there confusing questions, would you add or...
remove anything from the guide, did you like/dislike parts of the guide, etc. The focus group will occur in a private setting at a time and location that is convenient for you. The total time commitment for your participation is approximately two hours. The group discussion will be audio-recorded and later analyzed to better understand your feedback, which will be used to improve the family decision guide.

**Potential Risks**
Discussing your experiences with providing care at home for your family member with an advanced life-limiting illness may be distressing. You may feel grief, sadness, or anxiety when recalling the experience. You may also experience some loss of privacy from sharing your experiences with the researchers and other participants in the focus group. The research team will identify resources and supports that will help you deal with any adverse reactions to the focus group discussions.

**Potential Benefits**
Although there are no immediate benefits, your participation in this study will help to improve a support tool for FCGs who look after someone with advanced life-limiting illness. As a token of appreciation for participating in this study, each participant will receive a $25 gift card to Tim Horton’s.

**Confidentiality**
The nature of a focus group means that other participants will be aware of the conversation. We request that participants respect the privacy of others in the group by not revealing the identities of participants to others and not discussing what others said in the group, but we cannot guarantee that this request will be respected. Your identity and discussion will be kept strictly confidential by the research team. The audio-recorded focus group discussion will be transcribed and all personal identifiers (such as names and places) will be removed. All data records will be stored in a locked filing cabinet at a secure location and electronic files (e.g., audio-recordings and transcripts) will be kept on a password-protected site at the UBC Okanagan. After the study is completed, your information (data) will be stored in accordance with UBC Okanagan policies and procedures. Data that has had all personal identifiers removed will be stored electronically for a minimum of 5 years at UBC Okanagan in Dr. Robinson's research site and will be password protected. At the end of the study audio-recordings will be erased, paper copies shredded, and CD's destroyed. Access to your data will be restricted to the research team and the research project coordinator. All those who have access to the data will be trained in the appropriate methods of handling and storage of confidential data. If necessary, an experienced research assistant will transcribe the audio-recordings and will be educated on confidentiality issues and will be required to sign a confidentiality form.

**Contact Information**
If you have any questions or desire further information about the study, you can contact Dr. Carole Robinson at (250) 807-9882. If you have any concerns about your rights or treatment as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at (604) 822-8598 (toll-free number 1-877-822-8598) or the UBC Okanagan Research Services office at (250) 807-8832.
**Consent**
Your participation in this study is entirely voluntary. You may refuse to participate or withdraw at any time without any consequences or explanation. By signing this consent form, you are agreeing to participate in this study and acknowledge that you have received a copy of this consent form for your own records. By signing this consent form, you do not waive any of your legal rights.

I have read the information and I have had a chance to ask any questions about the study and my involvement. I understand what I have to do and what will happen if I take part in this study. I freely choose to take part in this study and have received a copy of the consent form.

__________________________________________________________________________

Participant’s Signature and Date

If you choose to participate in this project, please indicate if you would like to receive a project summary by providing us with contact information.

Email:

__________________________________________________________________________

Mailing address:
Appendix E: Demographic Information for Bereaved Caregivers

THE UNIVERSITY OF BRITISH COLUMBIA | OKANANGAN

Caring at Home for Someone With an Advanced Life-Limiting Illness: Family Decision Guide

Demographic Information for Bereaved Caregivers

Date of Focus Group: _________________  Participant ID #:________________

Your gender: Male ☐  Female ☐  Your age: ____________

What was your relationship with the person you provided care for (circle one)?
   Spouse ☐  Parent ☐  Child ☐  Other (specify)_____________

Marital Status (circle one): Married ☐  Common-Law ☐  Widow/Widower ☐  Single ☐

Number of Children:  Sons_____  Daughters_____

Ages of Children:  Sons_____  Daughters_____

What was the illness of the person you provided care for? ___________________

When was your family member diagnosed with this illness? ________________________

How long did you care for your family member at home? _________________________

Did you or your family member receive any assistance or support from anyone else or other organizations?
   No ☐  Yes ☐

If yes, from whom (check all that apply):
   Other family/friends ☐  Voluntary organization ☐  Health system/social workers ☐

What types of supports have you received?
   __________________________________________________________
   __________________________________________________________

Are you currently employed outside the home? Yes, full time ☐  Yes, part time ☐
No/Retired

Educational Level *(check all that apply)*

High School ☐ College/University (Undergraduate) ☐ College/University (Graduate) ☐
Appendix F: Interview Guide

Caring at Home for Someone with an Advanced Life-Limiting Illness: Family Decision Guide

Objectives of focus group: The purpose of the focus group is to gather feedback that will be used to improve a decision aid for FCGs of someone with an advanced life-limiting illness. The ultimate goal of this research is to help FCGs provide better care at home for as long as possible, while also maintaining their own health and wellbeing. We are interested in speaking with individuals who have experience with providing home care for their family members with an advanced life-limiting illness in a focus group setting.

Script: Thank you for coming today to participate in our focus group. You are here because you have cared at home for someone with an advanced life-limiting illness. Your experience and expertise is very valuable. We know that providing care at home can be both rewarding and challenging. We are developing a tool to assist FCGs to provide the best care at home, for as long as possible and would like your feedback on how to make the tool more useful.

Here’s what we are going to do…(participants will complete the tool and then engage in discussion to give feedback).

Before we begin the discussion, there are a couple of things we need to talk about. My job is to listen, help keep the discussion on track, and to make sure that everyone’s ideas are heard. We will be recording the conversation and taking notes as we go along so we don’t miss anything that is said.

We understand that you all may have different perspectives, and we are interested in hearing what each of you has to say. We want to hear different ideas so don’t hesitate to jump in with a new or different thought.

Everything discussed with the research team will remain confidential. Because we are talking in a group, we unfortunately cannot control what other participants do with the information discussed. We ask that each one of you please respect the privacy of everyone else in the group by keeping everything that is said inside this room. Do you have any questions or concerns before we start?

Questions
General Impressions
We are interested in hearing about your general impressions of the guide. Probes:
• What did you think of the guide?

Response to Tool
• Did you understand the information presented in the guide? Was anything confusing?
• Was anything missing? Did the guide capture what was important to you about providing care?
• Were there things you think could have been left out?

**Language – we would like the guide to be useful to both men and women:**
• Is the language used appropriate for both men and women?
• Are there any words or phrases you think need to be changed to make it more appropriate for both men and women?

**Position of Caregiver – sometimes the person who is providing care is a spouse, sometimes an adult child or other relative, and sometimes a friend.**
We would like the guide to be helpful to all kinds of caregivers.
• Does the guide work for you as a spousal caregiver? Adult child?
• Do changes need to be made that would make it more appropriate for different kinds of FCGs?

**Timing**
• Thinking back to when you were providing care, when would a guide like this have been useful for you?

Do you have any advice for us as we move ahead with developing this guide?
PARTICIPANTS NEEDED FOR
RESEARCH CONCERNING CURRENT FCGS CARING FOR A FAMILY MEMBER WHO HAS ADVANCED CANCER

We are looking for volunteers to take part in the study:

Caring at Home for Someone who has Advanced Cancer: Family Decision Guide

As a participant in this study, you would be asked to: take part in an interview. You would review a Family Decision Guide and give your opinion on how easy the guide is to understand, and how important and helpful you think this decision guide would be to FCGs.

You would be asked to take part in one session, which would take around 2 hours of your time.

In appreciation for your time, you will receive a coffee gift card from Tim Horton’s.

For more information about this study, or to volunteer for this study, please contact:
Janelle Zerr
Graduate Nursing Student, UBC Okanagan
250-863-1409 or Email: Janelle.zerr@gmail.com

This study has been reviewed by, and received ethics clearance through a University of British Columbia Okanagan Behavioural Research Ethics Board.
Appendix H: Information Sheet

An Evaluation of a Family Decision Guide:
Making Decisions About Providing Care at Home for Someone who has Advanced Cancer

Study Background
The purpose of the research is to develop and improve a decision aid for family caregivers of someone with advanced cancer. The basic goal of this research is to help family caregivers offer the best possible care at home, for as long as possible, while also maintaining their own health. We are interested in speaking with people who are providing care at home for a family member who has advanced cancer. These individuals will help in the development of the guide by giving their opinions and suggestions while going through the decision guide.

Participants
We are looking for 12-20 current family caregivers (both men and women; aged 19 and over) to participate in a face-to-face interview. Family caregivers can include anyone who provides the majority of the emotional and/or physical care to the individual with advanced cancer. This includes immediate family, friends, and neighbors.

Study Procedures
You are being asked to voluntarily participate in this study because you are providing care at home for a family member with advanced cancer. We are interested in your views about the decision guide, ‘Caring at Home for Someone with an Advanced Life Limiting Illness: Family Decision Guide.’ Your participation will involve going through the decision guide while verbally telling us your thoughts and feelings about such things as how easy the guide is to understand, how relevant and how helpful you think the guide might be in relation to your experience of providing care at home. We will ask broad questions about the decision guide: i.e. what are thoughts, were there confusing questions, would you add or remove anything from the guide, what did you like/dislike about the guide, etc. The total time commitment for your participation is approximately 2 hours.
As a token of appreciation for participating in this study, you will receive a $10 gift card to Tim Hortons.
For more information about this study, or to volunteer for this study, please contact: Janelle Zerr, Graduate student, Nursing, University of British Columbia Okanagan 250-863-1409 or email: janelle.zerr@alumni.ubc.ca
Appendix I: Consent to Contact Form: Cognitive Interviews

An Evaluation of a Family Decision Guide: Making Decisions About Providing Care at Home for Someone who has Advanced Cancer

Study Background
The purpose of the research is to develop and improve a decision guide for family caregivers of someone with advanced cancer. The basic goal of this research is to help family caregivers offer the best possible care at home, for as long as possible, while also maintaining their own health. We are interested in speaking with people who are providing care at home for a family member who has advanced cancer. These individuals will help in the development of the guide by giving their opinions and suggestions while going through the decision guide.

Participants
We are looking for 12-20 current family caregivers (both men and women; aged 19 and over) to participate in a face-to-face interview. Family caregivers can include anyone who provides the majority of the emotional and/or physical care to the individual with advanced cancer. This includes immediate family, friends, and neighbors.

Study Procedures
You are being asked to voluntarily participate in this study because you are providing care at home for a family member with advanced cancer. We are interested in your views about the decision guide, ‘Caring at Home for Someone with an Advanced Life Limiting Illness: Family Decision Guide.’ Your participation will involve going through the decision guide while verbally telling us your thoughts and feelings about such things as how easy the guide is to understand, how relevant and how helpful you think the guide might be in relation to your experience of providing care at home. We will ask broad questions about the decision guide: i.e. what are thoughts, were there confusing questions, would you add or remove anything from the guide, what did you like/dislike about the guide, etc. The interview will occur in a private setting at a time and location that is convenient for you. Interviews will be conducted by phone for out of town participants. The total time commitment for your participation is approximately 2 hours.

As a token of appreciation for participating in this study, you will receive a $10 gift card to Tim Horton’s.

For more information about this study, or to volunteer for this study, please contact:
Janelle Zerr, Graduate student, Nursing, University of British Columbia Okanagan
250-863-1409 or email: janelle.zerr@alumni.ubc.ca You can also complete the consent to contact below and Janelle Zerr will contact you.

Consent to Contact
I am interested in knowing more: ☐ Yes ☐ No

Signature: ___________________________________________ Date: _____________________

Phone/cell number: ________________________________ Email: _____________________
Appendix J: Informed Consent to Contact: Cognitive Interviews

THE UNIVERSITY OF BRITISH COLUMBIA | OKANANGAN

Faculty of Health and Social Development
Fine Arts and Health
3333 University Way
Kelowna, B.C. Canada V1V 1V7

Informed Consent Form: Cognitive Interviews with Persons Who Are Providing Care at Home for Their Family Member who has Advanced Cancer

Caring at Home for Someone with Advanced Cancer: Family Decision Guide

Principle Investigator:
Carole Robinson, School of Nursing, University of British Columbia Okanagan, 250-807-9882

Co-Investigators:
Joan Bottorff, School of Nursing, University of British Columbia Okanagan
Barbara Pesut, School of Nursing, University of British Columbia Okanagan
Janelle Zerr, Graduate student, Nursing, University of British Columbia Okanagan

Study Background
The purpose of the research is to develop and improve a decision guide for FCGs of someone with advanced cancer. The basic goal of this research is to help FCGs offer the best possible care at home, for as long as possible, while also maintaining their own health. We are interested in speaking with people who are providing care at home for a family member who has advanced cancer. These individuals will help in the development of the guide by giving their opinions and suggestions while going through the decision guide.

Funding
This facet of the research is not funded.

Study Procedures
You are being asked to voluntarily participate in this study because you are providing care at home for a family member with advanced cancer. We are interested in your views about the decision guide, ‘Caring at Home for Someone with an Advanced Life Limiting Illness: Family Decision Guide.’ Your participation will involve going through the decision guide while verbally telling us your thoughts and feelings about such things as how easy the guide is to understand, how relevant and how helpful you think the guide might be in relation to your experience of providing care at home. We will ask broad questions about the decision guide: i.e. what are thoughts, were there confusing questions, would you add or remove anything from the guide, what did you like/dislike about the guide, etc. The interview will occur in a private setting at a time and location that is convenient for you. The total time commitment for your participation is approximately 2 hours. The discussion will be audio-
recorded and later analysed to better understand your feedback, which will be used to improve the decision guide.

Potential Risks
Talking about your experiences providing care at home for someone with advanced cancer may be upsetting. You may feel grief, sadness, or anxiety when thinking about the experience. You may also experience some loss of privacy from sharing your experiences with the researchers. The research team will identify resources and supports that will help you deal with any difficulties you experience from the interview discussion.

Potential Benefits
Although there are no immediate benefits, your participation in this study will help to improve a support tool for FCGs who look after someone with advanced cancer at home. As a token of appreciation for participating in this study, each participant will receive a $25 gift card to Tim Horton’s.

Confidentiality
Your identity and discussion will be kept strictly confidential by the research team. Notes will be taken on the audio-recorded discussion and all personal identifiers (such as names and places) will be removed. All data records will be stored in a locked filing cabinet at a secure location and electronic files (e.g., audio-recordings and transcripts) will be kept on a password-protected site at the UBC Okanagan. After the study is completed, your information (data) will be stored in accordance with UBC Okanagan policies and procedures. Data that has had all personal identifiers removed will be stored electronically for a minimum of 5 years at UBC Okanagan in Dr. Robinson's research site and will be password protected. At the end of the study audio-recordings will be erased, paper copies shredded, and CD's destroyed. Access to your data will be restricted to the research team and the research project coordinator. All those who have access to the data are trained in the appropriate methods of handling and storage of confidential data. If necessary, an experienced research assistant will transcribe the audio-recordings and will be educated on confidentiality issues and will be required to sign a confidentiality form.

Contact Information
If you have any questions or desire further information about the study, you can contact Dr. Carole Robinson at (250) 807-9882. If you have any concerns about your rights or treatment as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at (604) 822-8598 (toll-free number 1-877-822-8598) or the UBC Okanagan Research Services office at (250) 807-8832.

Consent
Your participation in this study is entirely voluntary. You may refuse to participate or withdraw at any time without any consequences or explanation. By signing this consent form, you are agreeing to participate in this study and acknowledge that you have received a copy of this consent form for your own records. By signing this consent form, you do not waive any of your legal rights.
I have read the information and I have had a chance to ask any questions about the study and my involvement. I understand what I have to do and what will happen if I take part in this study. I freely choose to take part in this study and have received a copy of the consent form.

Participant’s Signature and Date

If you choose to participate in this project, please indicate if you would like to receive a project summary by providing us with contact information.

Email: _________________________________________________________________

Mailing address: ___________________________________________________________

Please indicate if you would like to be contacted with information about future studies.
☐ Yes       ☐ No

[Tick box with yes or no] then if yes, contact information (email/mailing address).

E-mail: _________________________________________________________________

Mailing address: ________________________________________________________
Appendix K: Demographic Information for Current Caregivers

Caring at Home for Someone With an Advanced Cancer: Family Decision Guide
Demographic Information for Current Caregivers

Date of Interview: _________________ Participant ID #: ______________

Your gender: Male ☐ Female ☐ Your age: ___________

What is your relationship with the person you provide care for (circle one)?
Spouse  Parent  Child  Other (specify) ___________

Marital Status (circle one): Married  Common-Law  Widow/Widower  Single

Number of Children:  Sons _____  Daughters _____

Ages of Children:  Sons _____  Daughters _____

What is the illness of the person you provide care for? ________________

When was your family member diagnosed with this illness? ________________

How long have you been caring for your family member at home? ________________

How many hours a week do you provide care? ________________

Do you live in the same house/residence as your ill family member?
No ☐ Yes ☐

Do you or your family member receive any assistance or support from anyone else or other organizations?
No ☐ Yes ☐
If yes, from whom (check all that apply):
Other family/friends ☐ Voluntary organization ☐ Health system/social workers ☐

What types of supports do you currently receive or have you received?

______________________________________________

______________________________________________

Are you currently employed outside the home?
Yes, full time ☐ Yes, part time ☐ No/Retired ☐

Educational Level (check all that apply)

High School    College/University (Undergraduate)    College/University (Graduate)
## Appendix L: Table of Suggested Changes from Focus Groups

Table 1

<table>
<thead>
<tr>
<th>Page number</th>
<th>Images/Tables</th>
<th>Language</th>
<th>Content</th>
<th>Understandability/Comprehension</th>
<th>Sequencing/Flow</th>
</tr>
</thead>
<tbody>
<tr>
<td>First impression</td>
<td></td>
<td>Add some explicit language about conversations for what is wanted at end of life. Add words like “hospice” and “palliative care” to the guide. Helpful to initiate conversations. Participant wanted resource list that was available and affordable in the area.</td>
<td>Need to review guide several times to understand.</td>
<td>Good bones, but some gaps. Asks for info in formats that aren’t user friendly.</td>
<td></td>
</tr>
<tr>
<td>Page 1</td>
<td>Appropriate language for men and women. Suggest using “palliative care” instead of “life-limiting illness”</td>
<td></td>
<td>Questions need to be asked differently to address more clearly whom the guide is for.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Page 2</td>
<td>Need to personalize the guide, suggests using images, which would make it lighter as well.</td>
<td>Needs more detail re: funeral, will, legal affairs Helps to get prepared ahead of time especially if rural and avoid running by the seat of your pants Some said guide was great with practical things and was asking the right questions, but not so great with the emotional aspect. Indicated that guide is full of questions and no answers—suggests adding some side bars with extra information.</td>
<td>Reminded one person of an income tax form and others agreed. Needs softer font. Format doesn’t fit sensitive emotions of the process. Needs to look more appealing. Guide is currently in a raw format. Suggests adding photos, quotes, putting little facts or preambles that can act as dialogue.</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Page 3</td>
<td>Getting time to yourself as caregiver so that you can manage. “doing enjoyable things”</td>
<td>Q3. Lacks transition, confusing Change to “how are you managing now? Place an X on the line</td>
<td>People say that it reads as a study, where info is being collected, not as a helpful tool for</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Page 4</td>
<td>Info confusing in table format, especially going back and forth between pages 4&amp;5 Jumping back and forth between pages 4&amp;5 for the table was confusing. Participants were shown the amended table and that was clearer.</td>
<td>makes readers feel like the author of the guide doesn’t understand their situation</td>
<td>representing how you are managing? caregivers.</td>
<td></td>
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<td></td>
<td>Advantages &amp; disadvantages weren’t a fit for all. Advantages &amp; disadvantages: Having to list 2 was not helpful. Instead say “what are the main advantages and disadvantages.”</td>
<td>Chart was hard to understand. Confusing—would be helpful if someone went thru guide with them Far too burdensome during caregiving.</td>
<td>All were in favor of splitting the chart. Split the chart and answer the question directly below the question. Consensus that the information should be kept, but must be reformatted. This section was moved farther back into the guide. The order was changed significantly to allow for better flow.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Page 5</td>
<td>Table was very confusing.</td>
<td>Definitions were helpful.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Page 6</td>
<td>Preamble is overly wordy and not clear. Needs additional, tangible support to</td>
<td></td>
<td>One said she wouldn’t have gone through any</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Page 7</td>
<td>Language unclear—whose perspective are they answering from. Add fear to the list. Felt it was unnecessary to add fear to the list as other descriptors indicated or encompassed fear.</td>
<td>make guide effective.</td>
<td>of it b/c it would have given her a headache.</td>
<td></td>
<td></td>
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<tr>
<td>--------</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td>----------------------</td>
<td>-----------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Page 8</td>
<td>Highlighting language like underlining YOU was good.</td>
<td>Include <strong>doctor</strong> under source. List specific agencies like palliative care, home care nurses etc.</td>
<td>One didn’t understand the purpose, what would happen once the guide was filled out. Personal resources, add legal and specify,</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


| Page 9 | Add equipment  
And differentiate b/t inside and outside the home respite, personal support.  
Resource list is great, but where does the caregiver go from there to access resources and know the costs etc.  
Need to be explicit about end of life care and choices. | Eliminate “Understanding how others made this decision” was viewed as unnecessary and confusing. | One felt the guide was too lengthy for someone in the process of caregiving. |
|---|---|---|---|
| Page 10 | Add resource list  
Add resource list  
Examples of agencies | | |
| Page 11 | Most important are the caregiver and the patient and participants felt that we had covered that.  
How is | Not enough space for writing  
Layout was unhelpful for page 10-11. Consider revising format. | |
<table>
<thead>
<tr>
<th>Page 12</th>
<th>hospice accessed? Include.</th>
<th>Q18 is overly wordy-simplify please Q18 repetitious, but participants said to leave it in.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Was anything missed?</td>
<td>Nothing strongly positive in the guide-love is a reason people care at home Another said that there was no other suitable option, that’s why she cared at home. Another said it was because they were so close relationally. Counseling support would be helpful</td>
<td></td>
</tr>
<tr>
<td>Language</td>
<td>Clarify between meaning of financial support-“paying bills or can’t afford</td>
<td>Suggests that someone should go through the guide with the caregivers. Participants liked that small print was eliminated/Avoided.</td>
</tr>
<tr>
<td>Advice for us?</td>
<td>More information needed regarding end of life decisions, DNR, advanced care planning</td>
<td></td>
</tr>
<tr>
<td>----------------</td>
<td>-----------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>How was the experience?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Back cover</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Focus group number 1 is documented in black.
Focus group number 2 is documented in blue.
Focus group number 3 is documented in green.
Appendix M: Table of Suggested Changes From Cognitive Interviews

Table 2

<table>
<thead>
<tr>
<th>Page number</th>
<th>Images</th>
<th>Language</th>
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<tbody>
<tr>
<td>Title Page</td>
<td>Change or add a photo to increase ethnic diversity</td>
<td></td>
<td>A family caregiver decision guide</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Page 1</td>
<td>Delete space for family photo as it contributes to negative emotion.</td>
<td>“Last completed on this date” viewed as harsh.</td>
<td>Insert intro statement to explain revision dates.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Page 2</td>
<td>Delete colon after preposition in page title. Delete “long-term”?</td>
<td>Add arrow to complete circle from step 4 to step 1?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Page 3</td>
<td></td>
<td></td>
<td>Relocate images to bottom of page 4.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Page 4</td>
<td>Omit exercising, replace with “Helping family member keep active -involved in meaningful activities”</td>
<td>More specifics regarding what end-of-life decisions entail (e.g. Medical Directives, POAs, wills etc.)</td>
<td>My loved one's pain control</td>
<td>Remove top section from page 4 and move to bottom of page 3.</td>
<td></td>
</tr>
</tbody>
</table>
| Page 5 | Title: omit "and its not always easy to keep healthy"  
Omit "exercising" from "Keeping active"  
Replace "enjoyable" with "meaningful" | Make Financial support and legal support more explicit with examples. | Move the "Overall, how well am I managing now?" question to the bottom of page 4.  
Reverse the order of "keeping active" and "Doing meaningful things," then move both to the bottom of the list. |
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Page 6</td>
<td>Cannot keep up with important tasks</td>
<td>Add box: Exhaustion</td>
<td></td>
</tr>
<tr>
<td>Page 7</td>
<td>Add box: Supports family member’s well-being</td>
<td>Suggest intro sentence like “Tick those that apply.”</td>
<td></td>
</tr>
<tr>
<td>Page 8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Page 9</td>
<td>No changes on this page, correct?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Page 10</td>
<td>Replace middle image of “depressed” man with a more positive and ethnic diverse image.</td>
<td>Add “Getting personal care for your family member” to the list. Add an appendix on back cover of guide of</td>
<td></td>
</tr>
</tbody>
</table>
provincial/national services and supports with web address and phone numbers where possible. This helps address the strong request for more information on services.

<table>
<thead>
<tr>
<th>Page 11</th>
<th>Delete first line option of “Home”</th>
<th>What are my <strong>best options</strong> if the needs for care change and I can no longer care at home?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Page 12</td>
<td><strong>In reflection, what are my best options if I can no longer keep caring at home with the resources I have now?</strong></td>
<td>Delete first line option of “Home”</td>
</tr>
</tbody>
</table>
| Page 13 | **Big heading at top of page: Ask yourself...**

What do I need to do now to continue caregiving?

What do I
<table>
<thead>
<tr>
<th>Page 14</th>
<th>What questions do I have for a family doctor or...</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>If I have any questions for a family doctor or...</td>
</tr>
<tr>
<td>Page 15</td>
<td>Who can I contact for help? Or replace with: List questions for a family doctor or other health care professional about alternative places of care here.</td>
</tr>
<tr>
<td></td>
<td>Helpful to list specific health care agencies, (e.g. homecare, Red Cross, Palliative care team etc.)</td>
</tr>
<tr>
<td></td>
<td>Add another heading: Banking</td>
</tr>
<tr>
<td></td>
<td>Often only one spiritual leader or lawyer, whereas often several friends and family. Suggest allocating space accordingly.</td>
</tr>
<tr>
<td>Page 16</td>
<td></td>
</tr>
<tr>
<td>Page 17</td>
<td></td>
</tr>
<tr>
<td>Page 18</td>
<td></td>
</tr>
<tr>
<td>Back cover</td>
<td>Add an appendix on back cover of guide of provincial/national services and supports with web address and phone numbers</td>
</tr>
</tbody>
</table>
where possible. This helps address the strong request for more information on services.

*Change all third-person to first person throughout entire guide to connote that the guide is a personal tool for the caregiver. Furthermore the change in person is thought to initiate personal ownership and action towards decisions.

*Change “loved one” throughout guide to “family member.”

Words in Red indicate that the word has been added or has replaced a previous word.